

## Editorial

# Sitting down for freedom so that others may stand up

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Rosa Parks died on 24 October 2005. She might have led an unremarkable life working as a seamstress, getting married, running a home and dealing with the ups and downs of daily life. She would then have lived in a constant state of fear because 'we didn't have any civil rights. It was just a matter of survival, of existing from one day to the next. I remember going to sleep as a girl hearing the Klan ride at night and hearing a lynching and being afraid the house would burn down' (Academy of Achievement, 2005). Rosa Parks' life was imbued with fear but, as she boarded a bus in Montgomery, Alabama, she had no plans to become a heroine. She was going home after work; no doubt her feet ached, she was tired and wondering what to cook for dinner. A chance encounter presented her with an opportunity to make a stand against injustice that would change not only her life but also the lives of millions of others. Rosa Parks refused to give up her seat on the bus to a white person. She was arrested and fined \$10.00 plus an additional \$4.00 for court fees (*New York Times*, 2005). It could have been much worse. This single act of defiance could have cost her her liberty or even her life, particularly during the ensuing civil unrest in which black people boycotted the bus service for over a year, challenging the entrenched legal and social systems that enforced racial segregation. In 1955, black people in Alabama were second-class citizens, subject to myriad petty restrictions, injustices and cruelties solely because of their colour. Yet one single act of defiance led to the dismantling of the whole edifice of state-sanctioned segregation and oppression in Alabama.

This is not to say that oppression ceased. It reformed, dressed in new clothes and moved on. When Daw Aung San Suu Kyi went home to Burma to nurse her dying mother she found herself living under a political regime that brooked no opposition, a military dictatorship which responded to any dissent with brutality and

force (Burma Campaign UK, 2005). As in Alabama, people lived in fear of a knock on the door, of arrest without charge or trial. In publicly opposing the regime through non-violent means, Daw Aung San Suu Kyi's very existence became a challenge. In consequence she lost her freedom but, in doing so, has become one of the world's most well-known champions of democracy for a country about which few might otherwise have heard (The US Campaign for Burma, 2005).

Both Rosa Parks and Daw Aung San Suu Kyi demonstrate the truth of Burke's argument that 'all that is necessary for the triumph of evil is that good men do nothing'. The actions of one person can be the first step to a change in the world. Both Rosa Parks and Daw Aung San Suu Kyi took that step and, through their example, invite others to use their freedom to bring about that of others (The US Campaign for Burma, 2005).

It is perhaps easy to think that in order to do so one must have a great political or social cause, yet oppression, discrimination and injustice are all around us every day. Our attitude to others, the value that we either give or withhold from them, is evident in our actions towards them. Readers with experience of care giving will recognise the many ways in which this withholding occurs. One of the authors of this editorial was at one time in charge of a rehabilitation unit for adults with physical disabilities. Taking patients shopping was a lesson in discrimination: identifying the shops in which staff subtly conveyed that people in wheelchairs were unwelcome, drivers who deliberately parked in front of the person in a wheelchair waiting to cross the road, the hostile silences on entering a café. All of these speak volumes about the ways in which those who see themselves as social insiders regard people who do not fit established norms (Elias and Scotson, 1994). The other author was, for a year, reliant on crutches and experienced just as many petty,

insidious attempts to restrict his everyday life, even when lecturing to medical students.

In this issue we present papers about a number of social groups whose members are perceived as social outsiders and outcasts. We begin with a paper about drug and alcohol dependence to which UK society, and possibly others, has at best an ambivalent attitude. George Best's alcoholism attracted very little criticism; he was lauded as a wonderful footballer long after he had ceased to play. In contrast, a prime time UK TV soap opera has graphically demonstrated the unpleasant consequences of alcohol dependence – incontinence, vomiting, blackouts – features that invite censure. Had George Best been plain Joe Public there would have been no glamour in his drinking. Luger and Sookoo's paper (p. 167) tackles the issues faced by families of those who are drug and alcohol dependent and emphasises the isolation, sheer helplessness and despair that spouses and parents experience in trying to cope. As one of the participants explains, 'It's a shame when your husband is drinking or if the son is taking drugs. It's your fault. Blame yourself'. The speaker is right; blame is what alcoholics, drug addicts and their families receive, and this is doubled if they are also part of another minority group. Getting involved and trying to help can also attract censure of the 'why waste time with such people?' variety. Yet, as this paper shows, voluntary and statutory service providers willing to make some modest changes could make a world of difference.

Making that difference could also be the role of faith ministries if we include them as a particular type of service to communities and individuals. Rosa Parks' refusal to move to the back of the bus gained support from Dr Martin Luther King Jr, and it was through him and the Baptist church that the civil rights movement gathered momentum. All the major religions provide teaching on the care of the sick and the importance of healing for the mind and soul. However, as Chinouya's paper makes clear, some forms of illness carry a heavy stigma, particularly when associated with sexuality. Living with HIV means coping both with the physical aspects of AIDS, which will eventually lead to death, and also with social ostracism. Faith leaders, according to Chinouya, seem ill-equipped to cope with either of these factors, pleading lack of resources, finance, qualifications, recognition by statutory providers and a host of other reasons why they should not be involved in actively opposing discrimination and oppression. Rosa Parks' and Daw Aung San Suu Kyi's actions were not influenced by whether or not there was a budget available or a risk analysis; they took what they regarded as the morally right course of action at the time. However, and in fairness, neither had to deal with what is really at the root of Chinouya's paper – how we think about sexuality and sexual practices. Like the rest of the

population, faith leaders shy away from talking about sex in public spaces, particularly if it is associated with practices that may be relegated outside of social or faith-based norms. Like drug and alcohol addiction, sexuality is present but never mentioned.

Not talking about things in this way creates cultures of silence. Discrimination, injustice and oppression can continue either because no one dares to speak up or because no one actually knows what is going on. Three papers in this issue show how cultures of silence serve to reinforce stereotypes and myths that further disadvantage those who are already severely marginalised through the application of blame and censure. Rozario's paper (p. 187) deals with genetic issues among Bangladeshis, in particular the place of consanguineous marriage in transmitting risk factors. The practice of consanguineous marriage amongst Bangladeshi and Pakistani Muslims attracts criticism from members of the dominant social groups in the UK who argue that it accounts for an unusually high incidence of certain, otherwise rare, genetic conditions and increased mortality (BBC News, 2005; Butt, 2005). For the critics the solution is simple: Bangladeshis and Pakistanis should end the custom of cousin marriage (Butt, 2005). However, the evidence regarding the transmission of genetic disorders is far from straightforward. Epidemiological findings indicate that consanguinity may carry some risks for some genetic disorders but not all. Certain conditions may occur only in particular families. Genetic testing is available to those at risk, and the number of tests available looks set to increase. Moreover, cousin marriage is practised by other social groups that do not attract the same degree of criticism (Darr, 2005). Nevertheless, South Asian parents who have disabled children are blamed by health professionals and made to feel personally responsible for their children's disabilities in a way that other groups are not (Ahmad *et al.*, 2000). Blame and guilt militate against meaningful dialogue between the two camps, and effectively prevent either from developing a clear understanding of the real genetic risks as opposed to the mythology.

Turner *et al.*'s paper (p. 197) deals with dementia; losing one's mental faculties in later life is something that is both joked about and feared. As this paper shows, understanding of this condition is mediated by cultural norms and values about old age and the type of care that demented people should receive. Where dementia is seen as part of normal ageing, something to be expected and accepted as fate, people may have quite different expectations from those who regard it as a sign of organic disease. Such conceptualisations impact on expectations, access to useful information and care. In particular, this paper highlights some of the various myths that surround care of the elderly. Among the dominant culture there is a belief that immigrant groups, especially South Asians, will provide

care within the family, while among South Asians there is the stereotypical perception that members of the dominant culture will send elderly people into care homes. Both betray naïveté about the realities of caring for someone 24 hours a day, seven days a week, week after week without any prospect of respite, and the strain that this places on family members who try to cope alone.

Scanlon and Woods's paper about breast cancer awareness (p. 211) continues the theme of cultures of silence through examining the ways in which marginalised social groups lack access to appropriate information. Such lack of access reinforces their marginal status to their detriment. Breast cancer is one of the most common and potentially treatable forms of cancer. The incidence of the condition among members of black and other minority groups is predicted to rise as immigrant populations take on the patterns of health and illness found among the dominant culture. Lack of awareness about breast cancer means that women will not examine their breasts regularly, take advantage of mammography, or seek out early diagnostic services. Consequently they will present late for treatment and, like the parents in Rozario's paper (p. 187), receive blame for doing so.

The remaining two papers in this issue represent attempts to bring about change, to make a difference to the treatment and care of patients and clients. Novak-Zezula *et al* (p. 223) report on the Migrant-friendly Hospitals Project, a European project that aimed to improve the health of migrant people who do not share the same language as their healthcare provider, through the introduction of professional interpreting services. Interpreting is a highly skilled activity that involves more than merely substituting one set of words for another. It requires an understanding of the total message to be communicated; this includes the words used, the accompanying tone, emphasis and non-verbal signals. To achieve this it is sometimes necessary to undertake what Launer (1978) described as 'legitimate deviation'; that is, moving away from the exact words of the speaker, seeking to clarify and encapsulate meaning rather than provide a verbatim translation. Putsch (1985) added another dimension to meaning by arguing that both the professional and the interpreter must take account of the degree of linguistic equivalency between the two languages involved. Linguistic equivalency refers to the translation of concepts or specific terms. For example, there may be no equivalents for terms such as 'allergy' or 'depression', and consequently these may have to be expressed using very different terminology as the interpreter moves from one language and view of the world to another. Even concepts that initially appear to translate easily may acquire very different connotations, as the individual moves into a different language and culture. Relying on relatives is not acceptable because

they may lack the skills required or feel too embarrassed to transmit fully information about topics such as menstruation that are not normally discussed. The Migrant-friendly Hospitals Project demonstrates ways in which good practice can be implemented within the context of very different healthcare systems and cultures. We hope to publish a second paper about this project in the next issue.

Finally, Dogra's paper (p. 233) presents another approach to change through the medium of professional education in medical schools. The findings of her interviews with 62 informants demonstrate a willingness to include cultural diversity within the curriculum, but also highlight the difficulties in gaining acceptance and status for what is regarded as an emergent field. What is needed, at least as far as medical schools are concerned, is a coherent 'educational framework that will make it clear where and why it is being taught'. Institutions can be frustratingly slow to change, and in the meantime their clients miss out on benefits that might improve their lives. Like the dominant white majority in Alabama and the military junta in Burma, those in power are reluctant to give up what they regard as their right to maintain the status quo, which acts in their favour. Change may be promised, but always for the future. It is those at the margins, the dispossessed, who truly effect change by their refusal to comply with social bargains in which they are made inferior to others. Rosa Parks and Daw Aung San Suu Kyi brought about change, from within their own communities. Through them, oppressed people were able to re-evaluate themselves, rather than let others do so for them, and in doing so take their rightful places in society.

**Note:** We hope to publish a paper about Rosa Parks during 2006.

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