

**GUEST EDITORIAL**

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**LEPROSY AND STIGMA**

David Seddon\*, Janet Seeley\*\*

Leprosy is a chronic mycobacterial disease with primarily skin and nerve manifestations. It is also a socially constructed 'condition' with far-reaching implications for the attitudes, feelings and social behaviour of all concerned – those who have the disease and the condition, those with whom they interact, and those who find it difficult or refuse to interact with them. Indeed, leprosy has become a stereotype of a stigmatised condition; if someone talks of a person being 'like a leper', we know immediately that the person is being shunned and is being excluded in some way from society.

Leprosy is sometimes responsible for physical impairment and disfigurement and in some cases also for mental impairment. But, arguably more significantly, leprosy also gives rise to reactions and responses whose roots lie, not so much in the disease itself, or in its physical or mental manifestations and consequences, but rather in ideas about 'normality', 'difference' and 'acceptability', and in fears of contagion and contamination – in the stigma attached to the condition. The lessons learned from the experience of stigma for people living with leprosy, serve as a stark reminder for those who hope for the removal of stigma from the lives of others living with chronic conditions.

One of the great hopes of anti-retroviral therapy for people living with HIV, for example, is that if HIV and AIDS are seen to be manageable chronic conditions, the stigma so frequently and widely attached to them will subside. Indeed, assertions are being made that this is so (1) but if one turns to look at the experience of people who have been living with leprosy, which, unlike HIV and AIDS is a curable condition, one might doubt such optimism. The collection of papers in this issue tell of the persistent stigmatisation experienced by so many people who have had leprosy, or, who have a family member who has had leprosy.

Repugnance at deformity, revulsion at visible ulcers or wounds, and – above all - the fear of contagion (which also applies in the case of HIV/AIDS), can perhaps be understood if people have little knowledge of the causes of the disease and the condition. Perhaps the

reasons why 'leper' has long been used as a term for people who have been cast out, or rejected, can also be understood where knowledge of transmission is limited and the disease is considered contagious. But, stigma is not only the result of a person's revulsion at deformity or concern about 'catching' the disease and thereby developing the condition. It often also implies a judgement or moral statement – the 'leper' is 'unclean', perhaps because of some misdeed or sin. Perhaps the victims are at least to some extent, themselves to blame. This applies also in the case of HIV/AIDS, where there is not only widespread concern about 'catching it' through touch, or indirect contact, but also a degree of moral condemnation linked in part to the supposed modes of transmission (sexual intercourse, whether homosexual or heterosexual, drug use and shared needles, etc.) and in part to a vaguer notion of blame.

Physical deformity or impairment is not a necessary condition to provoke stigma. It is not only the people suffering from leprosy as a disease, or from the condition (impairments) that may result from it, who are stigmatised. People from the families of those who have suffered with leprosy may have no impairment themselves, but their association with someone with the disease taints their life. 'Courtesy stigma' (2), which affects people related to, or even friendly with, a person who has had leprosy, may seem irrational to those who know how leprosy is contracted; but stigma is seldom rational. The impact of so-called 'courtesy stigma' weighs heavily on many people's lives, affecting even their marriage and employment prospects. As Waxler (3) observes, leprosy provides an example of the social transformation of a disease from a medical condition to a condition, that has significance and meaning in society.

If one looks at the history of leprosy, one finds a disease bound up with fear and strong beliefs. Opala and Boillott (4) in their study of leprosy in Sierra Leone, show the importance of understanding people's world view in order to counter stigma and fear. They categorise three different world views in Sierra Leone of people living with leprosy: 1) as victims of dangerous powers beyond their control; 2) as manipulators of dangerous powers and 3) as morally corrupt people. If one is seen as a victim of misfortune rather than being morally corrupt, the response from people around one will be rather different and the impact of treatment on diminishing stigma also very different. Thus, if leprosy is seen to be a person's own fault or the fault of his or her family, one can comprehend why everyone associated

with the affected person suffers discrimination. Countering such beliefs lie at the heart of rehabilitation for people affected by leprosy.

Effective treatment has done a considerable amount to diminish the threat of leprosy and thus to diminish stigma: 'in the past, leprosy was viewed as a severely stigmatising condition that progressively devalued and marginalised the affected persons; finally to culminate in segregation, away from homes and society, in colonies of similarly deformed people. During this process, not only did society devalue them, but they also rated themselves lower on the value chain. The scenario is different today' (5). But as the papers in this issue clearly illustrate, although undoubtedly things are better than they were, leprosy continues to be a scourge. The disease, and the stigma and social exclusion that so often attach to it, persist in many places, particularly in South Asia.

The papers in this issue of the Asia Pacific Disability Rehabilitation Journal, concerned as they are with leprosy in South Asia, reveal the continuing significance, medical and social, of this disease, condition and social phenomenon within the sub-continent. This is not to underplay the progress that has been achieved - in the treatment of leprosy as a disease, in health policy and programmes more generally (including through 'community based rehabilitation'), and in social attitudes towards the condition on the part of health practitioners, social service workers and the wider community – but simply to draw attention to the fact that the issues associated with leprosy have not entirely gone away and that stigma in particular, remains a major concern.

\*Professor of Development Studies

School of Development Studies, University of East Anglia

Norwich, NR TJ, UK

e-mail: j.d.seddon@uea.ac.uk

\*\*Senior Lecturer in Development Studies

School of Development Studies, University of East Anglia

Norwich, NR TJ, UK

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Three hundred of the most practical and useful disability resources are listed in the Source International Information Centre directory and CD-ROM, "Disability, development and inclusion: key information resources". The information, compiled as part of the Disability Knowledge and Research Programme, is aimed at organisations working with disabled people in developing countries. It covers a wide range of themes including human rights, gender, poverty and mainstreaming, as well as planning and management of disability programmes and service delivery relating to children, community-based rehabilitation, mental health and HIV and AIDS.

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