

## Book Review

### **‘Don’t treat me like I have leprosy!’ Tom Frist ILEP, London, UK, 1996.**

The author sets out to guide three categories of people; 1) those presently involved in Hansen’s disease work, 2) those who have no experience now but may become involved, and 3) people interested in helping any stigmatized and discriminated group.

Part I provides an overview of the leprosy problem as he sees it. Frist looks at the goals of leprosy work, progress in achieving these goals in relation to the physical, psychological, spiritual, social and economic aspects of the problem. He discusses issues such as who speaks for leprosy sufferers, integration, roles of various agencies, resources and the ‘correct’ image of leprosy.

Frist posits the final goal of Hansen’s disease work as ‘to eradicate the disease and to help persons affected by it “normalize” their lives and achieve true social integration.’ He claims that this can take place only when there are changes in persons providing services and the public as a whole as well as in persons affected by the disease.

The author touches on the crux of the matter under psychological goals, that is, the failure of present and past health education efforts by care providers and educators to reduce stigma attaching to leprosy. He then asserts that ‘For leprosy stigma to reduce, the public, the provider ... and the person affected by the disease must learn the new reality of the disease ... not only learn, but come to truly believe that the old images of leprosy are no longer true., Only then will their attitudes and behavior change’.

Frist’s description of the problem is thorough and methodical, the facts provided are useful and enlightening and the framework claimed to be holistic. Unfortunately, his framework lacks cultural and religious elements and so is likely to miss crucial deeper understanding which could lead to effectively removing of the problem. Leprosy occurs in many countries where western, scientific, secular notions of health and illness, treatment and cure are not commonly held. Such cultures often have their own unique medical systems, their own way of explaining illness and their own means for dealing with it.

Foreign care providers in such settings need to be aware of the traditional cultures in which they operate. In this area of inquiry trained social scientists can lend vital insights into the culturally specific aspects of stigmatization.

Frist’s first model for attitude change is that knowledge leads to change of belief which then leads to change in attitude and behaviour. This is attractively straightforward but misleadingly simple. The wealth of literature and research on attitude change serves to illustrate that the process of change is complex and protracted. Studies in other fields could help those who attempt to bring about attitude change in relation to leprosy. Some examples are ‘diffusion of information’ based on programs to reduce smoking, raise the rate of childhood immunizations. Distinct elements of attitudes need to be studied to identify which are most likely to be ‘changeable’.

Part II provides a plan of action to promote normalization. There follows the Frist formula for achieving this. In order to bring about “normalization” changes must be brought about on three fronts, that of the people affected by leprosy, the society in which they live and finally in the service providers themselves. In order to be successful, programs designed to bring about ‘normalization’ need to be relevant, effective, efficient, sustainable and fair.

The primary step in this formula is to change ourselves. Here Frist suggests a second model of attitude change; if we base our behavior, not on our prejudices, but on sound scientific knowledge, then after such changed behavior 'we will often find that our attitudes will soon change as well'.

Next comes the identification of 'prime movers' or allies in society in the process of social change. Prime movers are to be organized and a project set up after investigating the problem in the area, gathering information in relation to the medical, psychological, socio-economic, support services related to the problem. What are the obstacles to social integration? Analysis of information will lead to the plan of action and identification of areas to be addressed. Detail is given on setting up support services and in such a way transforming the society in relation to leprosy.

Detail is also given on transforming the leprosy world. Integration and the dismantling of segregatory institutions and programs are advocated. '...it is imperative for all Hansen's disease-specific organisations to review their missions, ... names, ...symbols, ... fund raising strategies...'

Finally, Frist deals with who pays, the reduction of expenses and the evaluation needed to assess the progress of transformation. He provides a suggested Normalization Index for calculating progress in physical, spiritual, social and economic normalization for both the individual and a community.

Here the author presents his formula in a systematic and logical way with accurate and clear information. His formula advocates a systems approach to transforming society, to change services, infrastructures and community based programs.

Unfortunately Frist has also fallen into a trap when he said 'Health practitioners, because of their activist orientation, have an understandable tendency to begin with inputs (interventions) ... and assume that the outcome (desired changes) will occur automatically'. Frist's formula seems to be an input assuming a desired outcome. If it is applied in cross cultural situations regardless of the specific cultural insights, it may well lead to undesired negative effects. It is a pity that Frist has not consulted experts like Green and availed himself of the wealth of research literature available on attitudes and attitude change, stigma and stigma reduction.

Most would agree with Noordeen, who in 1991 mentioned several factors including social stigma which '...led to leprosy control losing considerable ground...'. Unfortunately, the WHO response of introducing MDT and the push for 'elimination', while reducing registered prevalence dramatically, has not addressed the stigma issue. Future prospects of leprosy control may be bright with 'major reductions in prevalence foreseen'; however, issues of social stigma are left unresolved.

One wonders if Frist's systems approach and formula for transformation has actually been used anywhere? What were the effects? Perhaps such a project should be tried as a pilot? It would be useful to have information on the actual successes and shortcomings of such an approach.

Frist is correct to suggest that the reduction of stigma with all its ramifications remains a long term aim of leprosy work. While his book may 'fill part of the literature gap' in this area, it remains to be seen if his formula provides an adequate framework to bring about changes or whether its weakness—that of disregarding traditional cultural and religious basis for much prejudice—will prove to be a fatal flaw.

*Jeanette Hyland*