Imagine for a moment you are responsible for finding a groom for your daughter. You will apply various techniques, perhaps talking to people in your social circle or perhaps through relatives you will begin to put out the fact that you are seeking a match. You may resort to an online matchmaking site, such as Saadi.com. Whatever method you use there will be a point at which you have a prospective candidate and you begin to make enquiries about the young man. His family background, his personal habits and known behaviour as well as his economic position will all be taken into consideration.

If you find out that his father is a person affected by leprosy will you continue to consider him a match for your daughter? This scenario occurs across India on a regular basis. To many people the answer is a resounding ‘no’ but the justification will be much less clear.

You may already know that leprosy is a disease like others that can be treated, and as it is not hereditary you need not worry that just because the young man is the son of a person affected by leprosy he is an unsuitable match for your daughter. However, it is likely that there will be other factors at play in your decision making process. You may be fearful about what other people will say; you may still harbour ideas that the family must be cursed to have such a disease; you may choose to ignore the scientific facts completely and not wish to put your daughter at ‘risk’; you may fear that if others find out your family will be shunned or classified lower in the social hierarchy. All of it is baseless but this is what happens all the time.

The socio-economic effects of leprosy, as this suggests, are many and varied. People affected by leprosy find it difficult, for example, to get treatment for non-leprosy related disorders from private hospitals if they have visible signs that mark them out as having leprosy. Whilst working in a leprosy hospital in South India, I met a pregnant woman, visibly affected by leprosy, who, at the time of her delivery, found herself being sent from one hospital to another until she could find one that would admit her.
A personal friend called Narayana (name changed) lived in rural Andhra Pradesh with his ageing mother and took treatment from a leprosy colony clinic once a month. I lived and worked in the colony at that time and on each visit I praised him for staying integrated in the wider community. By contrast, he always expressed a desire to come and live in the leprosy colony. He told me that as a result of having leprosy he had reduced sweating in his legs and arms — an effect of skin damaged by leprosy bacilli — so when he worked out in the fields in the hot sun he appeared to sweat more heavily across his face, chest and back than his fellow workers. He dreaded someone commenting, dreaded the possible confrontation and the possibility that people might find out he had leprosy. In the end he left his mother, community, work and home in favour of a leprosy community without work but where he need not hide his disease. This is not unusual, people with leprosy often wish to keep their condition hidden for fear what may happen to them and their family.

One of my work colleagues in the leprosy hospital in Andhra Pradesh would boldly go to the local town but with his deformed hand always in his pocket. He would go about his business taking every precaution that no one would see his hand and perhaps confront him with the fact that he has leprosy.

When I moved to Delhi to manage an organisation marketing products made by people affected by leprosy, an ex-pat resident volunteer confided in me that she found the husband of her housekeeper to be a most suspicious character: ‘He’s always slouching with his hands in his pockets and if caught unawares his behaviour was sheepish, somehow secretive’. It transpired that he too had leprosy and was afraid that his wife would lose her job and their accommodation if ‘madam’ knew.

Loss of sensation in hands and feet has far reaching socio/economic implications. Imagine drinking a hot glass of tea from a steel tumbler and then putting your tumbler down and discovering you have blisters on all your fingers; or straining hot rice and not realising that the steam is burning the back of your hand. Loss of sensation in your feet means that if a thorn goes through the sole of your sandal into your foot you will probably continuing walking until you have a deep wound, all the time not realising what you have done. Those are very common events amongst people who have had leprosy and have been left with reduced or no sensation in their hands and feet. How can a farmer work in his fields if every step might see him injuring his feet? How can a weaver tie his loom if his fingers are too insensitive to feel the knots in the yarn?

In a society that still has negative attitudes to leprosy the difficulties experienced by people who have grown up in leprosy colonies are multiple, and in some cases hardly different from those of their parents. A young woman whom I shall call Sunita works in leprosy rehabilitation in a large city far from her leprosy colony home. Her parents are both disabled by leprosy but have a progressive view of education and have encouraged all their children to study and obtain qualifications. Sunita tells me that all through college and later, wherever she has lived and worked, she has never once told anyone about her background. She has not been able to bring her best friend home even though other young people growing up with her in the leprosy colony have done so. She has a strong personality in many ways but in this area of her life she fears rejection.

In a leprosy colony in Faridabad there are strong tensions between the old leprosy affected founder members and the young next generation who do not have leprosy. Wishing to share in the management of the community the young people resent the power of the elders, whilst the elders feel the young do not appreciate the struggle they went through to build up the community.
For one entire generation the strength and support of the extended family was absent in many leprosy colonies, leaving parents (many of whom had not been educated themselves) with a heavy burden to raise children without any role models for the children to emulate. The consequences have included poor performance in school which has adversely affected the ability of the first non-leprosy generation to find employment. ‘I had no one to guide me or show me what to do’ a young man from a leprosy colony told me when I asked why he had dropped out of school at 8th standard.

All these examples illustrate the significant impact of leprosy on the life of the individual and family. The fact is that disease sometimes brings with it socio-economic effects that have no direct bearing on the scientific facts of the disease. There is a need for research and scholarship, for constantly updated awareness and training to understand and respond to the needs of communities facing such challenges.

Enacted stigma is ‘any action or behaviour that acts out a negative attitude towards a person or group.’ Given that these types of socio-economic effects may be observed in all communities where forms of enacted or internalised stigma are found, it might be useful to look at some examples of enacted stigma and consider what part we can play in reducing the discriminatory behaviour that is so prevalent in many societies.

Practicing non-discriminatory behaviour ourselves can act as a positive example for change. In an article published in the internal journal of a development organisation working in India, Sunil Singh describes being amongst scheduled caste groups in Bihar and being shocked to discover that amongst them there existed discriminatory behaviour. This is not entirely surprising given that the structure of Indian society is based, to a large extent, on caste and hierarchical systems. One can see that people might think: if one lot discriminates against me why should I not discriminate against someone else whom I perceive to be lower down some scale than I am?

Sunil’s wonderful response was to encourage his team to be a positive example by taking tea with the so called lower group. This simple act is important because many discriminating taboos in Indian society are food based. One hears stories of so called low caste people being refused tea in the village tea shop, and in my early work in a leprosy hospital in South India, I would often hear patients describe how they were turned away from the tea shop because their damaged hands gave them away as people affected by leprosy.

Dr. Lakshmanarao (name changed), a doctor in a small town in Andhra Pradesh, confessed to me in the early 1980s that he was afraid to treat leprosy patients in his small private practice. He was afraid of the disease (even though he was scientifically trained) and he was afraid of the impact on his own business if he was seen caring for people with leprosy. He admitted to focusing his thoughts on the matter when he met my colleague, a young nurse from the UK, who had come to work in the nearby leprosy hospital. ‘When I saw her, so young, and vibrant and beautiful, and realised that she never thought twice about working in a leprosy hospital far from her home and “comfort zone”, I looked again at my own motives for avoiding treating leprosy patients and realised they were unsound.’ He went on to serve the leprosy community for many years in his own private practice which remained lucrative.

So, sharing a cup of tea, shaking hands, providing services to and spending time in the company of people who are usually discriminated against are all acts which will bring into question the accepted position that it is fine to discriminate.

How we use language is also important. People affected by leprosy in their own charter delivered to the United Nations Human Rights Commission have asked not be called ‘lepers’. As a term of derision it has a long history, and the late Bernard Ka’owakaokalani Punikai’a,
IDEA’s President for International Advocacy from 1997–2007, speaks for many when he says: ‘We refuse to allow others to define ourselves, our humanity, by a disease.’ The challenge here then is to make sure that none of our language contributes to the demeaning of another individual. If we choose our language carefully, and keep correcting those who may unwittingly use derogatory terms, we will contribute to change.

In his article, referred to above, Sunil Singh says he convinced his team members to take tea with the low caste community by highlighting the fact that ‘he never thought to refuse’ tea and breakfast with people in a leprosy colony. His example worked and he influenced his team, but in the process he implied that his leprosy friends were somehow even lower than the group they were working with! Sunil and I have discussed the matter, and it was clear that for him, there is no question of not taking tea with a person because of their perceived place in society. But he accepted that, without him realising it, his words had implied something else.

In the last two decades more than 14 million people have been cured of leprosy, and many of those cured face social and economic difficulties as a result of having had leprosy. Leprosy communities in particular have exhibited some very interesting development models in order to cope with those difficulties. Long before it was common practice for development workers to encourage the formation of solidarity/support groups, people affected by leprosy were doing so. A typical example would be that of a South Indian leprosy colony I worked in as a nurse and an administrator for many years. As people were discharged from a nearby leprosy hospital, rather than cope with returning home they gradually formed a village beside the railways tracks near the hospital and, over time, realised that their strength lay in organising themselves. In 1961 they registered as a society, way before the concept was common practice in development circles. Policy makers and planners may consider studying models of development/community organisations across the barriers of stigma to see what can be replicated and acknowledged in their work.

How we respond to beggars is another factor for consideration. Government and civil society seeks to find solutions to activities like begging. In the current development climate where the trend is to uplift and empower marginalised communities, begging is seen as a demeaning activity. In his book, James Staples notes that people disfigured by leprosy, and therefore unwelcome in general society, use the very body that has been rejected by society to ‘earn’ a living through begging. In India we have all experienced that very forceful image of an amputated or deformed limb thrust in our face at a railway station or traffic lights. In the upturned world of begging then, the deformities that prevent them from getting employment elsewhere allow them to construct themselves as ‘marketable selves’. Group begging by people affected by leprosy shows a high level of organisation, planning and implementation, and makes shrewd business sense in a society where giving alms is a religious obligation.

This does not make begging good, anymore than disabled people peddling dope at street corners is good, but it shows choices and decisions and responses to events in life way beyond what we often see in so called ‘normal’ society. I would suggest we might be better trying to look at development from other perspectives, studying these examples in a fresh way and acknowledging their value instead of always seeking solutions that match the donor’s or government’s patterns. Especially when the problem seems to lie not so much with the beggar as with the society that causes begging.

The stigma experienced by so-called ‘lower castes’ in Indian society has been the very hook on which successive governments have drawn up pro-active policies, most notably reservation in education and government employment. Similarly, the stigma experienced by people with leprosy has been the driving force behind their organisation and planning, and
indeed their approach to earning. Stigma in itself is undesirable, but the response to stigma may be far from undesirable and should be studied and better understood.

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