EDITORIAL

Sustaining anti-leprosy activities requires radical changes

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The Global Strategy (2006–2010) defines sustainability as ‘the capacity of a programme to maintain quality and coverage of services at a level that will provide continuing control and further reduction of a health problem at a cost that is affordable to the programme and the community.’ This is a major challenge for leprosy having changed from a well supported, high priority specialised programme to one that is now mainly integrated within general health and social services. Radical re-thinking is necessary if we want to sustain early case detection, treatment, prevention of disability, and reduction in the consequences of leprosy including stigma.

Sustainability is a huge challenge to all leprosy activities everywhere. It is a common problem for all elimination and eradication programmes that have made great progress but now find it harder as the problem appears to get smaller, polio eradication being a good example where the end-game seems tough. The priority of leprosy relative to other health problems in a country diminishes as the number of new cases reduces, and the cost per patient treated steadily increases.

The common responses to sustaining leprosy services are to integrate, work harder, train to build capacity, maintain resources for leprosy and keep doing the same things we have always done. However, we need to question our motivation, what are we trying to sustain and why? Is it that we who have always worked in the cause of leprosy now feel our future is threatened, or as leprosy specific organisations that our whole reason to exist is being undermined? Andrew Green in 1998 warned that leprosy organisations should not see their own existence as an objective in itself. Do we genuinely want to ensure that quality services are sustained to those who need them irrespective of how they are delivered or who delivers them? Are leprosy experts an impediment to sustaining services?
Sustainability has been recognised, discussed and debated for over 20 years. Guidelines have been developed on integration to achieve sustainability. It was recognised in the 1990s that many components of the leprosy elimination strategy were not sustainable, however these were justified in terms of achieving a dramatic reduction in the prevalence of leprosy.

The importance of sustainability has been increasingly emphasised in global strategies since 2000. The key approach to sustainability has been integration of the delivery of leprosy services into basic health and primary care. Sustainability is fundamentally an ecological concept, but when applied to health care it tends to largely focus on financing. Attempts are made to ensure that leprosy funds do not find their way to assisting other programmes while being happy if funding from other sources support leprosy activities. Integrated programmes often become what has been termed ‘combined vertical programmes’ rather than truly integrated. However, many previously vertical programmes are, like leprosy, trying to integrate at the same time, into the weak, fragile infrastructure of primary health care. This has been recognised by WHO in their attempts in 2009 to re-vitalise primary health care on the anniversary of Alma Ata. One major constraint to integration is the capacity of basic health services to cope.

Training and capacity building have been seen as approaches to create sustainability and much has been invested in training programmes, training courses and training centres. High levels of staff mobility and staff turnover then continually erode this capacity. Are we training the right people at the right time? Is our training in leprosy fully integrated into basic training or just trying to fill gaps later on? Much has been said about getting leprosy embedded into all training curricula but probably not much has been done to achieve this. Maybe the concept of ‘leprosy training’ is flawed in terms of sustainability; perhaps the aim should be to ensure through advocacy that leprosy is included in training of all health care staff.

Leprosy programmes have been slow to develop areas such as integration, multidisciplinary research, involvement of people affected by leprosy, community-based rehabilitation and community participation. Many of these changes potentially threaten the position of those responsible for leprosy activities; we can be as isolated in our thinking and methods as people affected by leprosy. Research is a good example; leprosy research centres have become progressively isolated, using old technology, with little significant output. There is sometimes even criticism when leprosy researchers work in any other area than leprosy. Yet, the reality is that leprosy research is most productive when it is conducted in a multidisciplinary research environment which exchanges ideas, technologies and resources with other research areas.

Partnerships need to be re-thought, and new partnerships developed. Partnerships in leprosy often tend to be with like-minded partners rather than different, complementary and innovative partners – perhaps leprosy agencies need to interact more with agencies in the Neglected Tropical Disease network.

Prevention of disability is one area that has been innovative, with self-care, community and family involvement, groups of people affected by leprosy, and the use of available, affordable, acceptable appliances such as footwear. There are remarkable achievements in sustainable prevention of disability, which potentially is one of the most difficult areas. One reason for this is that health care staff or leprosy workers can do very little on their own, and to make progress in terms of coverage and sustainability, the ownership of prevention of disability had to pass to people and communities. Sustainability was achieved through recognising that the activities had to become the responsibility of people themselves.
Advocacy must play an increasing role to bring about change. Not doing or delivering services, but influencing those who are responsible to ensure that leprosy is included in health care and social care, and that people affected are fully included in all aspects of society. Effective advocacy requires very different skills and adopting different roles. There is not enough expertise in leprosy for leprosy workers to undertake all the activities needed in leprosy. Indeed, leprosy staff, by trying to do everything themselves, make leprosy activities less sustainable and prevent the full integration of leprosy activities and of people affected by leprosy. Radical change is needed; more of the same old approaches are not sustainable.

References