

Editorial

VOLUNTARY DONOR AGENCIES IN ANTILEPROSY WORK: PRESENT CONTRIBUTION AND PROBABLE FUTURE*

For 10 years or more, those engaged in antileprosy work have been aware of the possibilities offered by multi-drug therapy (MDT). It has been commonplace to speak in the abstract of rapid change. Now the reality of that change, with both its successes and its limitations, is becoming evident.

Today we are faced by a debate which, although at times tendentious, at least results from success. Just what are the tasks remaining in leprosy, and what are their scale? What is the time-frame in which we need to think? And who will support and undertake the continuing work?

Voluntary donor agencies, such as those in membership of ILEP, the International Federation of Anti-leprosy Associations, come to that discussion with a particular perspective, the traditional vision of not-for-profit charitable organizations in liberal democracies: to seek support for the needy, and to fill gaps in provision.

It must be stressed that this article discusses only the role of voluntary *donor* agencies, and does not deal with the extremely important contribution made by local associations in endemic countries. They are often the local partners of the donor agencies discussed here; and it is frequently they who do the real work in the field.

The financial contribution

The contribution of not-for-profit associations from industrialized countries in the field of leprosy has been and continues to be remarkable. Indeed, compared with other areas of support to developing countries, it is probably unique, for in leprosy work, it is voluntary agencies, not governments, that are by far the largest source of external funding.

During 1993, ILEP Members expected to provide approximately \$75 million dollars in grants. Total funds for leprosy from not-for-profit agencies will have been somewhat higher than this but ILEP, with 20 members based in 15 countries, does include all the

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major charitable bodies interested in leprosy. Only 3 or 4 of its members receive significant co-financing from their own governments. So, even taking account of the new World Bank soft loan for the Indian National Leprosy Eradication Programme, ILEP support far outweighs what is provided directly for antileprosy work by donor government sources.

The main intergovernmental organization concerned with leprosy, the World Health Organization (WHO), provides technical advice and consultants for governments, not funds for operational activity. Through the Tropical Diseases Research (TDR) programme, it does make some funding available for research. A part of the funds for both TDR and the general leprosy programme of WHO is provided by some Members of ILEP.

Coordination of support

ILEP is also unique among networks of voluntary donor agencies for the quality of financial and operational coordination between its members. The initial impetus for the Federation was and remains the desire of members to ensure that their funds are used wisely with the greatest possible benefit for people with leprosy.

That means avoiding wasteful duplication of funding but yet collaborating when necessary. Approximately one-third of all projects supported by members receive funds from more than one association. At the same time members are jealous of their own autonomy and each decides independently how and for what they wish to give support.

Thus, over the 27 years of its existence, the Federation has developed a set of tools to ensure coordination while retaining individual autonomy. Members meet once every 6 months to share news and discuss joint funding. For each project and most countries, a single member is appointed as 'coordinator' to be the channel for contact with all supporting members. Through an information network based on central registration of projects and standardized reporting systems (the infamous A, B and C Questionnaires!), members know what each other is supporting and how projects are progressing. In addition the Medical Commission ensures coordination of medical advice on matters of common interest.

This all sounds fine, but this structure is also feeling the impact of the success of MDT. To some degree, the system of coordinators presumes a geographical division of responsibilities between the members. Yet now, as attention increasingly focuses on the relatively small number of countries that have large numbers of people with leprosy, it is more common to see several member-associations operationally active in the same country. In such cases, members have a considerable need for enhanced working cooperation on the ground, in addition to their financial coordination. This is especially true regarding their relationship with national programmes and governments.

Public health, targets and the humanitarian imperative

For the most part, money given out by ILEP Members has been collected from the general public. As such, it is an expression of humanitarian concern by a great number of individual donors in many countries. There can be a temptation to discuss such generosity

in sentimental terms but it has very practical implications for the present debate about continuing needs in antileprosy work.

Individual donors put trust in the agencies to which they give. They expect their monies to have some direct positive impact on the lives of individual leprosy patients. In other words there are assumptions at play which are antithetical to a purely public health approach.

While individual donors are likely to be encouraged that their money will help in some way to 'reduce leprosy', they are also likely to be ill at ease if the greatest good for the greatest number is achieved at the detriment of particular individuals. This dichotomy is implicit in the differing statements of target adopted by ILEP and by WHO in response to the success that was seen by the late 1980s to be possible with MDT.

During 1988–90 an Expert Group of the ILEP Medical Commission, anxious to accelerate the use of MDT, looked at what could be recommended as basic, rather than optimum, conditions for MDT implementation, after what was already a decade of experience worldwide. To their technical proposals,¹ they added the idea that ILEP Members adopt a concerted time-specific strategy for MDT implementation.

This led in June 1990 to acceptance by members of their target of *MDT for all by the Year 2000*. It is notable on two counts. First, reflecting the hesitation of autonomous associations to be formally committed to common action, it is more a strong statement of determined intent than a fully fleshed-out coordinated strategy. Second, it follows the humanitarian imperative so important to members and the donors to whom they are responsible. It speaks of bringing a good to *everybody* who should benefit.

A year later the World Health Assembly, the governing body of WHO and an organ of governments, adopted what at first glance appears to be the similar target of *Elimination of leprosy as a public health problem by the year 2000, defined as the reduction of prevalence to a level below 1 case per 10 000 population*.² It differs, however, in significant ways. It is more managerial in its attempt to define a precise measurable target, and in the systematic way in which it has been pursued by WHO. It is more political in offering governments a dramatic achievement within a relatively short space of time.

Above all, however, it is less ambitious. It limits the horizon to 'leprosy as a public health problem' and defines that problem arbitrarily at a level which, while by no means easy to reach, can be seen as a practical possibility. There is an underlying assumption, difficult for the traditional humanitarian to accept, that there will still be people with leprosy whose problems either need not be seen as significant or who must be left to a later stage and further targets.

When is a case not a case?

Given the humanitarian viewpoint, a further difficulty, to which voluntary agencies have become more sensitive, is the definition of a case of leprosy now in use. When in 1988 the WHO Expert Committee on Leprosy, in its Sixth Report,³ limited the definition to *a person showing clinical signs of leprosy . . . and requiring chemotherapy* there was little reaction. It seemed to be a straightforward, if somewhat tautological, working definition.

Today we see the practical implications in radically revised global and country statistics on leprosy. Progress toward the elimination target as seen in the statistics is rapid only partly because of the undoubted impact of MDT. It is also because all those people

who are released from treatment, but who remain affected by damage from the disease, no longer fall within the definition of a case.

The Sixth Committee Report did go on to recommend that projects should maintain not only lists of the cases requiring chemotherapy but also lists of those *who have deformities and disabilities due to past leprosy* when released from surveillance and treatment. Sadly, this further recommendation has been largely overlooked. Now, for the most part, patients once released from chemotherapy surveillance are lost as far as any formal records are concerned.

In the days of lifelong monotherapy, the distinction was irrelevant. Today it is taking us time to adjust to a view of leprosy-affected people in two groups: a, those requiring MDT; and b, those requiring support for the physical and social sequelae of the disease. The definitions and statistics focus our attention on the first. Yet surely the second must also be of public concern?

Progress toward the ILEP target of MDT for all

ILEP figures are always based on returns (the ILEP B Questionnaire) from supported projects giving patient data as at 31 December of the year in question. Data at the end of 1992 show that MDT coverage in member-supported projects had reached 64%, an increase of 4% from 1991.⁴ This continues a steady rise since 1984 when coverage was only 8%. MDT coverage for newly-detected cases is even better, reaching 79% during 1992.

At project level, it is interesting to see that out of the 204 projects reporting over 500 patients under chemotherapy, only 41 had less than 50% MDT coverage. In all, 127, or 62%, were using MDT for over 75% of their registered patients. Perhaps inevitably, it is the largest projects that still have furthest to go; 5 out of the 11 with over 10 000 patients are below 50% MDT coverage.

These figures suggest that attainment of the ILEP target by the year 2000 in projects currently supported by members is by no means impossible. The target of *MDT for All*, however, was quite consciously phrased in more ambitious terms. It was always understood that it implied further action to help bring MDT to additional areas and projects not yet supported by members. That remains a considerable challenge.

Global MDT coverage, as reported by WHO in mid-1993, was 49%.⁵ Thus there are still significant numbers of people who are known to control programmes but are not yet receiving MDT. Furthermore, WHO estimates of the total number of people with leprosy suggest there is still a gap of around 760 000 undetected cases.⁵

ILEP Members are helping to overcome these gaps, first through support to numerous national programmes in order to bring complete leprosy control coverage to those countries. Such support may often be for drugs or training rather than the total programme costs. Given that governments in most countries have now accepted responsibility for leprosy control, this is a growing feature of support by voluntary donor agencies. Funding of numerous independent projects continues, but increasingly within the framework of national programmes.

Second are new initiatives, especially in India. In March 1993, 9 members, recognizing the challenge still to be faced in the country which has two-thirds of all registered patients, committed themselves to increasing their involvement. This has already led to additional drug grants, undertaking of 'AMPLE' register cleaning and rapid survey exercises in a

number of districts, and cooperation in provision of training for staff in districts which are to begin MDT implementation once the World Bank loan begins to flow.

The continuing load

Associations such as those in ILEP have long accepted the opportunities offered by MDT—to reduce drastically the bacteriological load and thus the pool of transmission, and to prevent disabilities by early cure. They have and continue energetically to support implementation of MDT.

Many, however, have always been reluctant to put all their eggs in that basket. They have never forgotten their original humanitarian concern for the whole patient. Today, around two-thirds of support by ILEP Members goes to leprosy-control programmes, often including care and rehabilitation components. Some 7% goes specifically to rehabilitation programmes.

For member-associations the recent ILA Congress (Orlando, September 1993) was significant for its debates and state-of-the-art lectures reflecting heightened awareness of the continuing tasks in leprosy, even if the year 2000 targets are achieved. Members took note that action will still be needed and financial support required for:

- Those difficult places which will not have reached the target of MDT for all or the target of prevalence of 1 per 10 000 by the year 2000: countries with civil war, geographically inaccessible regions, and those parts of major leprosy countries that have a weak health service infrastructure.
- Ensuring detection and treatment of the new cases which will continue to appear. Even if our optimism is proved right and transmission is being drastically reduced by the present implementation of MDT, new cases will continue to appear for years to come. Indeed ILEP figures show a considerable *rise* in new cases over the last few years (1992: 196 000; 1991: 156 000; 1990: 107 000).
And, of course, a global prevalence rate of 1 per 10 000 will still mean half a million people.
- Ensuring the care of disabilities, physical rehabilitation, and social re-integration of patients. Prevention of disabilities is now accepted as a normal part of any effective leprosy control programme *while patients are under MDT treatment*. Much more problematic is the question of who could or should provide any further care for the 30% or so of leprosy-affected people who are either directly left with disabilities or are at risk of developing deformities due to loss of sensation. Even with the most optimistic view of the successes to be achieved with MDT, it must be assumed that at least the present generation of patients so affected will require some care throughout their lifetime. That in turn means maybe a further 30–40 years of significant demand on health services.

Action on disability: are targets possible?

The target of MDT for All remains valid for the first two concerns just cited. Action on disabilities and the social needs of patients, however, calls for fresh targets and fresh clarity about the tasks to be undertaken.

In a sense these are the historical concerns of voluntary agencies in leprosy. Long before a cure for the disease was known, there were projects providing support to the individual sufferer. Nonetheless, there is much still to be made clear as we move into the next era of leprosy work.

When talking of leprosy-affected people beyond those needing MDT, what are the numbers? The WHO estimate published in 1992⁶ talks of '2–3 million' people having disabilities as a result of leprosy. The ILEP Medical Commission commenting on that estimate,⁷ considered the real figure for people with Grade 2 disability could be twice as high, so 4–6 million.

These are large crude guesstimates of very real chronic human problems. Before even thinking of targets for action, we need a much more sophisticated picture of what numbers of people with what kinds of problem are to be found where.

Next, collection of such data presumes that there is something which can be done. A great attraction of MDT is that relatively simple actions produce consistently positive and evident results: the patient gets better. To have similarly simple effective tools in disability care would be a great help and permit development of genuine 'disability control' programmes.

It is probably in the area of footwear protection that we come closest to simple widely accepted recommendations, but even here there are those who question the necessity and efficacy of footwear provision. Initiatives such as the Prevention of Sole Wounds Study, a joint project of ILEP Members, which is due to report its results in the near future, are small steps in the right direction.

Then, perhaps, the greatest question—who or which services should respond to the continuing needs of leprosy-affected people? Voluntary agencies are likely always to respond to calls for support from projects offering rehabilitation or a social service to a group of individuals. There is, however, a danger of thinking in terms of vertical programmes and unfairly providing to ex-leprosy patients services that are just as necessary to other people with disabilities.

A framework for looking at this problem was offered by Dr H. Srinivasan in his state-of-the-art lecture at Orlando⁸ when he spoke of the need to *transfer the technology of re-enablement* from specialized leprosy programmes while they still exist, to the staff of primary health care services, as well as to the patients themselves and their families. While this may well be the way forward, it poses a major challenge to voluntary donor agencies. It suggests a pattern of funding that is relatively alien.

Supporting systems or projects: the dilemma of associations

The humanitarian impetus is ill at ease with broad impersonal systems. Associations look for warm close relationships with the projects and initiatives they fund. This is possible with small local projects; it is more difficult with large government-run programmes. Yet Srinivasan's 'transfer of technology' conjures up images of large programmes training many thousands of PHC workers through short, frequently repeated courses. The personal dimension for both donor and recipient is diluted, if not lost.

The same difficulty exists as regards the future of leprosy control work under conditions of low prevalence. Here again commentators such as Dr P. Feenstra,⁹ who himself is a member of the ILEP Medical Commission, suggest that antileprosy work will

be based on general health workers at the periphery, with support from doctors at district level; and only at the national or regional level will there be staff possessing specialist knowledge of leprosy to provide a referral service.

The probability is that the response of voluntary donor agencies such as those within ILEP will be to support pilot programmes, initiatives by local associations, and specialist referral services with which they can maintain a close-working relationship. Grants to enable a government to deliver some standard service will be less common. When they do occur, it is likely to be for discrete identifiable parts of the broader programme, such as drugs or training.

A lasting commitment to leprosy

What is clear, however, is the continuing commitment to leprosy of those voluntary donor associations which have traditionally specialized in the disease. Inevitably, there has been serious thought in recent years, both inside individual associations and within ILEP as a network, about the long-term future.

It is noticeable that a number of members have concluded with a re-affirmation of their commitment to leprosy work. Others, by broadening the statement of purpose in their constitutions, have opened a window to future work in areas such as tuberculosis, dermatology, or general rehabilitation. In all such cases, however, they have stressed that activity in other fields must be linked with, or at least assist, their antileprosy work.

It is interesting that a recent consultation with members regarding the possible need for changes to the Federation as such, met with an overwhelming response to the effect that no need for change is necessary at present. The continuing tasks in leprosy are perceived by member-associations as so great that the coordination function of ILEP will be needed by them for the foreseeable future.

There is some danger, however, that associations which are not leprosy-specialized to start with will withdraw from supporting antileprosy activity. This has been seen with a couple that have left ILEP in recent years; and with other generalized Third World development agencies whose involvement in leprosy has been reduced or given no priority for growth. If attention is given only to the figures of declining prevalence due to MDT, even people and organizations with practical leprosy involvement may come to think that there is little left to do.

Nonetheless, there is little danger that humanitarian associations long-focused on leprosy will disappear from the scene. The oldest ILEP Member, The Leprosy Mission International, celebrates its 120th anniversary in 1994. It and its colleagues in ILEP will be around for a good few years yet. Indeed, it is probably fair to say that there will be voluntary agencies active in support of people with leprosy long after governmental bodies such as WHO have moved on to other organizational and political priorities.

Together with governments, WHO, and local associations, voluntary donor agencies seek to grasp the opportunity offered today by MDT. With their humanitarian origins and purpose, however, they do not forget that at the end of the day it is the stigma of deformity, not the bacterium, which is the human tragedy of leprosy.

In many fields, it is the traditional role of voluntary associations to fill gaps, to respond to needs that official bodies have not yet recognized or been able to deal with. Leprosy is no different. Voluntary support for antileprosy work will continue. In time there may be

links with other medical issues, but the commitment to leprosy will not disappear. As attention moves from MDT implementation to continuing care and social rehabilitation, it is voluntary donor agencies that will be in the forefront, together with their local partners in endemic countries.

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