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# The potential benefit of Primary Health Care to leprosy control

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#### The problem: no decline of leprosy on a world-wide basis

A century after the identification of the causative agent of leprosy, which ushered in a new era in the battle against this ancient and in many aspects unique disease, it is far from being controlled on a world-wide basis.

In recent years it has become more and more evident that the hopes associated with the introduction of sulphone therapy in the late 40's were unduly optimistic. Though leprosy mortality has declined drastically no tangible impact has been made on the incidence of leprosy. Modest advances in the reduction of leprosy cases in certain regions have been largely offset by population increases in countries where the disease is endemic.<sup>1</sup>

#### Causes, underlying and contributing factors

The anti-leprosy campaign has suffered from numerous deficiencies and constraints which may be summarized as follows:

#### INADEQUATE HEALTH CARE INFRASTRUCTURE

In developing countries more than 80% of the rural, nomadic and slum dwelling population has no access to adequate health services. This applies to leprosy patients as well: to them physical and psychological accessibility to general health services has been equally low; 1 leprosy patient out of 4 or even out of 5 may have some contact with health services<sup>2</sup> (and if so it may be asked how effective this contact has been). A discussion of the large discrepancy between registered leprosy patients (ILEP statistics) and the estimated number of actual leprosy cases in the world has already been published.<sup>3</sup>

### SHORTCOMINGS OF EXISTING HEALTH SERVICES

Staffed by inadequately trained and supported health personnel that are frequently divorced from the concerns, health problems and health needs of the majority of their actual and potential clients, existing curative and institutionoriented health services have been largely ineffective in their impact on the health status of their service population.

#### LEPROSY: NO PRIORITY PUBLIC HEALTH PROBLEM

With rare exceptions leprosy is not considered as a priority public health problem by health policy makers and, as a consequence, its control fails to attract necessary budgetary resources for special, vertically organized programmes. Confronted with a host of more pressing health problems public health authorities have been reluctant to deal with an apparently complex and unrewarding disease whose chronic nature and the slow effect of its chemotherapy require long-term action and hence a substantial resource commitment over an extended period.

In addition, leprosy aid has been traditionally considered the domain of charitable and voluntary agencies.

## DEFICIENCIES OF ANTI-LEPROSY CAMPAIGNS

Specifically the anti-leprosy campaign has suffered from:

- (1) Inefficient and ineffective use of scarce resources that have been largely allocated to cost-intensive leprosy facilities aimed at alleviating individual illness and suffering with no or little impact on the actual control of the disease.
- (2) Predominance of a clinical approach to leprosy control with heavy reliance on rehabilitation (tertiary prevention) and treatment (secondary prevention), i.e. chemotherapy of known cases to the detriment of a communityoriented strategy with public health measures and activities geared to primary prevention.
- (3) Failure to systematically apply available knowledge and epidemiological principles relevant to the control of leprosy in large-scale action, aimed at the protection of the population at risk by effectively interrupting the cycle of transmission (identification of bacilliferous patients, index cases, household as well as extrafamilial contacts, specific high-risk groups with appropriate chemotherapy, public health and surveillance measures).
- (4) Too heavy reliance on mobile health/leprosy units which have largely restricted their activities to the mere distribution of drugs due to pressure of time.
- (5) Inadequate case finding and case holding (follow-up) measures.

- (6) Shortcomings of presently available chemotherapy (based upon oral administration of dapsone) for large-scale campaigns in view of its inadequate action upon the epidemiological most relevant forms of the disease; the problem is further compounded by microbial persistance and drug resistance.
- (7) Administrative shortcomings; in the fight against leprosy there has been an abundance of dedication and good will which has not been matched by the same degree of professionalism, particularly in view of the adequate planning, programme formulation, implementation, co-ordination and evaluation of leprosy control or health services with leprosy specific activities.

#### UNDER-UTILIZATION OF EXISTING LEPROSY SERVICES

There has been considerable under-utilization of available leprosy services largely as a result of:

- (1) Ignorance about and indifference to early manifestations of the disease and its complications.
- (2) An unfavourable socio-psychological environment in which affliction by the disease has often been associated with social stigma, which in return has reduced the chances of early diagnosis, the effects of adequate intervention and the prospects of case holding.
- (3) Distrust of outsiders and outside health services (mobile units).
- (4) Neglect of the felt needs of the service population due to a service scope limited to leprosy care.
- (5) Mobility due to migration (the rural exodus) has impaired efforts at keeping registered patients under close control and surveillance. For a more detailed discussion of the inadequacies and constraints of past and present anti-leprosy campaigns as well as for additional references on this aspect see Buchmann.<sup>4</sup>

## The single most promising solution: an alliance with Primary Health Care (PHC)

It has been the interplay of these deficiencies and constraints that has prevented or at least ill-affected an effective control of leprosy. What is to be done in view of these sobering facts? To be sure, the control of leprosy is too complex and affected by so many interacting factors that defy ready made solutions. However, rigorous application of presently available knowledge and integration of leprosy-specific activities in PHC services may well be the most promising approach to overcome the present deadlock.

#### PREMISES

It is quite certain that we cannot adequately address the numerous constraints and deficiencies that leprosy control is confronted with but the single most

promising strategy seems to be by far an alliance with PHC if the following principles are agreed upon:

- (1) Community-oriented leprosy control measures receive priority over curative services geared to individual sufferers from the disease.
- (2) Emphasis should be placed on world-wide, inter-national, national or at least regional anti-leprosy strategies in contrast to sporadic, ill-co-ordinated leprosy campaigns.
- (3) The leprosy problem cannot be perceived as an isolated health problem that can be solved by a basically medical approach even if more potent drugs or an effective vaccine were available.

## THE POTENTIAL BENEFIT OF PHC TO LEPROSY CONTROL

PHC briefly defined as:

essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination. It forms an integral part both of the country's health system, of which it is the central function and main focus, and of the overall social and economic development of the community. It is the first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process<sup>5</sup>

seems to be the key to a more effective control of leprosy on a world-wide basis. Its concept and potential are ideally suited to remedy some of the major constraints and inadequacies that antileprosy programmes and activities are presently faced with. This postulate certainly needs some further elaboration.

In 1977 the World Health Assembly declared 'health for all by the year 2000' as its main social target and identified PHC as the appropriate means to the attainment of this ambitious goal. In 1978 140 member states unanimously adopted the Alma-Ata resolution declaring PHC as their health priority for the coming decades.

The social appeal to health policy makers has been evident: coverage of hitherto unserved or underserved populations who make up the vast majority of their constituency by low-cost but effective health services that transcend the conventional boundaries of medical care. PHC based on a multisectorial approach is likely not only to favourably affect health status of a given population but also to become a major factor in the overall development process with good health being a necessary prerequisite to socio-economic development as well as a result of it. From this recent development of the international health sector leprosy policy makers may draw several conclusions:

- (1) Health for all by the year 2000, a human right and a social goal aimed at social justice should be deliberately applied to actual leprosy sufferers as well as to populations at risk in developing countries where leprosy with rare exceptions is endemic and particularly prevalent among poorer segments of the developing societies.
- (2) To be effective the anti-leprosy campaign is dependent on the availability of a general health care or leprosy-specific infrastructure which have not yet been established. However, to the control of leprosy, a chronic disease, the establishment of a permanent, community-based health service infrastructure is of utmost importance, particularly in view of case finding and case holding, surveillance and other essential public health measures as well as complementary activities. Thus, to be effective leprosy-specific health services must be as close as possible to its potential service population in order to be able to intervene as early as possible and as regularly and long as necessary.
- (3) In addition to its quantitative benefits PHC offers considerable qualitative potential. Largely confined in their impact by their narrow service scope and their limited resources leprosy services are hardly able to effectively address the leprosy problem, its causative and contributory factors with the needed comprehensive approach. However, an alliance with PHC whose intersectoral strategy seems to be ideally suited to yield a more tangible effect on the incidence of the disease, particularly when combined with leprosy specific activities (e.g. chemotherapeutical segregation of the epidemiologically most important forms of leprosy) and other relevant public health measures. The relationship between a poverty-stricken environment with its implications on human life and the occurrence of leprosy has been sufficiently evinced. Poor housing, commonly linked to overcrowding, deficient sanitary conditions, inadequate hygienic practices, a precarious nutritional state, lack of education etc. are closely correlated with ill health in general and leprosy in particular. As a consequence, any effective approach to leprosy control has to address these highly interrelated factors which are but expressions of a larger complex reflecting a low level of socio-economic development. It is most probably the impact on the whole cluster of these interacting variables that will lead to a decline of leprosy as the historical trend of many (formerly) leprosy afflicted countries in Europe, America and Asia, particularly in the 19th and 20th century, seems to reveal.\*

\*The decline of leprosy in Great Britain, Norway, North America (where leprosy was introduced by Norwegian settlers), Hawaii, Japan, the Philippines, Taiwan, Hong Kong and Israel for example seems to reveal that chemotherapeutic action has not been the single

Thus with PHC becoming the explicit health policy priority in most developing countries its potential to leprosy control will be of ever increasing importance particularly as it succeeds in:

- (1) Establishing frontline health services even at a most peripheral level thereby covering large majorities of populations hitherto unserved by general health or leprosy specific services.
- (2) Taking into consideration the environment in which the health problem arises and lingers on.
- (3) Perceiving the patient's community, its involvement and active participation in health matters and processes relevant to socio-economic development as a major and perhaps the key variable that determines his own as well as his community's health status.

# Incorporation of leprosy services into PHC by effective resource sharing

An alliance of leprosy services with PHC schemes wherever they exist or the active promotion of PHC by anti-leprosy associations is likely to yield mutual benefit. The potential of the PHC strategy to the control of leprosy as outlined earlier is vast. On the other hand, leprosy services/agencies in order to become an acceptable and indeed accepted ally in the implementation of PHC will have to make some substantial inputs, too.

With assistance of WHO the elaboration of a conceptional framework for national PHC strategies and the formulation of specific programmes have received due attention. It is the implementation component where apparent deficiencies exist, particularly at grassroot level. In this most crucial phase substantial boosting is badly needed. This may well become a concern and indeed a future commitment of leprosy services and their funding agencies as the integration of leprosy control services into PHC implies a mutual resource sharing not only of financial but also of health manpower, management, training, logistic, supportive and supervisory capabilities.

## NEED FOR AND EXTENT OF CAPITAL INVESTMENT

The need for the establishment of a basic health care infrastructure or its adequate restructuring and reorientation largely exceeds the financial capabilities of developing countries and would by itself already exhaust annual provisions in national health development budgets. Even if one relies heavily on community participation and appropriate village technology for the set-up of a

most important factor in the regression of the disease. In these countries, the decreasing incidence and prevalence of leprosy has long preceded the sulfone era beginning in the late 40's of this century. For detailed references on this aspect see<sup>4</sup> pp 31-36.

physical PHC-infrastructure (PHC posts/units or centres) and in spite of its deliberate low-cost approach and its favourable input/output ratio (potential services provided in relation to potential service population) there is a tremendous need for financial assistance.\*

Considerable inputs are needed to achieve maximum coverage. It is the enormous quantitative demand for health services in rural areas that makes capital investments relatively cost-intensive. Inputs would cover building material, basic equipment, essential drugs as well as necessary investments to assure adequate training and reorientation of PHC specific and general health personnel, respectively. Funds for logistic and supervisory support are equally needed.

In the past NGOs have contributed their fair share to health services development and it has been particularly the anti-leprosy associations that have taken up a considerable part of the financial burden for investments relevant to leprosy-specific health services. In view of past experiences it is most likely that anti-leprosy agencies will continue to raise substantial funds enabling them to share in financing PHC programmes with regard to their potential benefit to leprosy control. On the other hand, at least in the long run, they will be more or less obliged to do so. In spite of their financial resource potential the establishment of a permanent service network required for the effective control of leprosy on a world-wide basis will be largely beyond their capabilities, even in 'priority countries' where leprosy presents a major health problem.

Nor, and this is at least of equal importance, will public health authorities tolerate the establishment of vertically organized, leprosy-specific delivery systems in the future. In many developing countries health policy makers have made it quite clear that for leprosy services to become functional they have to be incorporated into and work through existing health delivery channels and thus contribute to the running of the national health care system.

#### POTENTIAL OF PHC-SPECIFIC MANPOWER

If there is real political commitment to the PHC strategy (and not mere lip service to a socially appealing idea) and if, as a result, necessary funding will be made available, there will be a tremendous output of frontline health workers over this decade. Deployed in chronically underserved areas they will probably soon assure overall coverage by basic health services.

\*Based on personal experiences in the Southern Sudan external inputs to the construction and equipment of PHC facilities at grassroot level may vary from US \$200 to 400 depending on the extent of community participation and the local availability of building material. At supervisory level (PHC centres) these inputs will be more substantial as it is extremely difficult to commit local resources at this level and as a more permanent type of building may be required.

As these health workers are community-oriented, selected and thus likely to be trusted by their constituencies they will most probably remain communitybased with a social role and community influence to build on.

To any effective future anti-leprosy strategy frontline health workers (variously named community health workers, CHWs, primary health workers, PHWs) are of greatest value and should be perceived as the backbone of any systematic anti-leprosy campaign. It will become a tremendous challenge to fully exploit the potential of these PHWs to the ultimate benefit of leprosy control.

In the past, various, mostly promising efforts have been made in this direction. In Ethiopia,\* Sierra Leone,  $Togo^{\dagger}$  and several other countries leprosy workers representing rudimentary frontline health services have been effectively used in basic health care after reorientation and upgrading of their formerly limited skills. To leprosy control these specialists-generalists are of greatest benefit.

Though these examples are limited to countries and regions where leprosy has been highly prevalent and where anti-leprosy associations have been committed to the control of the disease over an extended period the contribution of leprosy services to general health care in terms of establishing a basic health service infrastructure and deploying a rather devoted and effective health manpower in rural areas has been considerable.

#### INVOLVEMENT IN REFINED PHC-PROGRAMME FORMULATION, TRAINING AND SUPPORT OF PHC-WORKERS

In most countries, however, it may be the concern of leprosy agencies and services how to participate in PHC-programmes safeguarding their leprosyspecific mission while supporting a comprehensive health programme. Acceptance by health authorities may be largely dependent on the leprosy agency's degree of commitment to become involved in the implementation of PHC, particularly at grassroot level. The PHC Programme of the Southern Region of the Sudan, supported partly by German Leprosy Relief Association (GLRA),

\*In Ethiopia the director of the National Leprosy Control Programme has been in charge of the national PHC-programme, too, a fact that well reflects the pioneering achievements of leprosy services in the establishment of a general health care infrastructure in various countries.

<sup>†</sup>In the northern part of Togo the outpatient clinic system set up by the National Leprosy Control Programme has virtually covered every rural community and has taken leprosy specific health services to its actual clients and potential service population on a regular basis long before this has become an established and commonly accepted principle of modern health policy. As in some other countries, the rudimentary health care system set up by leprosy services in rural areas has become the nucleus of a PHC system that is about to be established.

is a case in point. By its extensive involvement in the PHC programme in two large provinces of the Southern Sudan, GLRA has been able to appoint a PHC Liaison Officer to the Regional Ministry of Health for the two provinces and, as a result, considerably shape the implementation of the PHC concept, particularly its refined programme formulation stage. Thus due emphasis has been given to leprosy-specific activities of Community Health Workers who, during their 9 months' initial training (alternated with field work) have been considerably exposed to leprosy-specific or leprosy relevant health knowledge. In addition, particular skills have been imparted to CHWs during leprosy specific training sessions arranged by the PHC Liaison Officer and organized by the National Leprosy Training Centre (NLTC) of the Sudan.\*

As the Regional Ministry of Health has neither been able nor willing to train and supply an adequate number of leprosy specific health personnel the potential of a training centre of this kind lies in conveying leprosy relevant knowledge and skills to general health workers who with rare exceptions have only rudimentary or even outdated notions of leprosy and its control.

Supervision of (frontline) health personnel in the sense of guidance and support is of vital importance to the effectiveness of any health service and particularly to PHC workers serving remote areas. In leprosy control programmes supervision has been perceived as a crucial element and has consequently received adequate attention. As a result, considerable experience has been acquired in the support of auxiliary leprosy personnel at peripheral level including the provision of continuous in-service on/off site training opportunities. This expertise may well be exploited to the benefit of leprosy integrated PHC services.

#### Conclusion

In spite of considerable efforts and financial inputs over the last three decades no breakthrough has been made on the actual control of leprosy which, due to population increases, may even be on the rise. The discrepancy between 3 million leprosy patients registered (which does not necessary imply their effective treatment) and 11-12 million cases estimated by WHO constitutes a tremendous challenge to those committed to the control of this ancient disease, in particular to the 24 member states of the International Federation of Anti-Leprosy Associations (ILEP) whose worldwide assistance benefits about 80 countries where leprosy constitutes a health problem.

As vertically organized leprosy programmes should be considered outdated since they are neither economically nor technically feasible on a large-scale

\*In addition, the NLTC offers specific training courses to more qualified health personnel involved in the PHC programme such as qualified nurses and medical assistants. basis nor health-politically and psychologically acceptable future anti-leprosy strategies must be geared to an alliance with other relevant health services and forces that may be instrumental to the control and ultimate eradication of leprosy.

The PHC concept has emerged as a most promising strategy to assure health for all by the year 2000 and to establish health services as an essential tool in the overall development process. To be more effective a comprehensive, a 'total health' care-approach to leprosy control is needed. This represents, however, no new idea. Holmboe, one of the distinguished Norwegian leprologists of the 19th century, with an amazingly modern vision proposed socio-economic assistance to those districts in Norway where leprosy was most prevalent in order to ameliorate the general level of hygiene and the mode of living.<sup>6</sup> It is this potential of PHC that is to be exploited and shared with as a crucial threshold seems to be reached today. The PHC train is about to get on its way and leprosy services, too often and for too long apart, should not be left behind by missing this splendid opportunity; they should get on that train now.

The flexibility and initiative, the ingenuity and commitment of antileprosy agencies and their field workers dedicated to combat against the disease throughout the world are ample guarantee that bold, innovative approaches to conquer leprosy will not go untried.

The commitment of leprosy associations to the promotion of the PHC concept and its implementation by effectively sharing their considerable financial and health manpower resource potential may finally decide on the extent to which they will be able to influence and shape national and regional PHC-programmes, their quality and direction to the ultimate benefit of leprosy control. In the long run, there seems to be no viable alternative.

# References

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