Leprosy control programs in general prioritize MDT for all, second priority is POD and finally rehabilitation. In order to improve the programs for rehabilitation, increase of patients responsibility for their own health and the introduction of so-called care packages are important steps to take.

The final conclusion of the analysis is that rehabilitation of leprosy disabled should be part of a general rehabilitation program.

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SELF CARE GROUPS : THE ALERT EXPERIENCE, ETHIOPIA

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The first self care groups were started in the ALERT, Ethiopia leprosy control progamme in 1995. They were started in response to two main problems: the increasing number of people who were dependent on the programme for their wound healing despite years of health education and the limited resources for traditional medical wound healing methodologies.

Group membership is voluntary and the outcomes are encouraging. The group members have taken up their responsibility to manage and monitor their own wound status and supply their own wound healing materials. If they wish, they may purchase canvas shoes and PVC boots at a subsidised cost from ALERT. The results show a reduction in the number of foot ulcers; most improvement occurs in the first six months of joining a group, but that improvement is maintained in the longer term. Hand ulcers seem to come and go more quickly and relate to working and seasonal variations. In addition, they pay more attention to their personal hygiene and appearance and some are now concerned about local environmental hygiene. Qualitative outcomes include: increased confidence to participate in society, restored dignity and self respect and a sense of belonging to the community. In December 1999 the number of groups had expanded to a total of seventy two.

The leprosy worker has had to change his / her role from that of a service provider to that of a self care group facilitator; but not all were successful in making this transition.

The remaining challenge is the sustainability and further development of the programme. A number of options are available to achieve this goal, namely: the National Tuberculosis and Leprosy Control Programme, community development organisations and the Leprosy Association.

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Re 412

REHABILITATION OF DISABLED PERSONS

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Rehabilitation of disabled persons can take many different forms according to the socio-cultural and political context in which it is undertaken. Some approaches have emphasised the restoration of the physical function of the client, while others have looked beyond to psychological and social well-being. Some have built on the expertise of professionals while others have emphasised the caring capacity available in the family and the community and sought to reinforce it. Besides providing a wide range of possible services to disabled persons, rehabilitation wants to change the attitudes which prevail in society as a whole and promote the integration of disabled people into society with equal rights and opportunities. Four dimensions are described which can be used to characterise and define rehabilitation projects based on the objectives which are defined for them. Thus, types or families of rehabilitation projects can be distinguished. Evaluation of rehabilitation projects should pose questions relevant to the type of project under consideration and should thus begin with a classification of the project as indicated above. Secondly, evaluation should consider the position of people with disabilities in a particular society and how the project contributes to meeting their needs. Questions concerning progress and performance should at least address :

1) Participation 2) Involvement of clients relatives and the community 3) Types of services offered and their utilisation/coverage 4) Outcome.

Questions and indicators will be presented which can be used in the evaluation of each of these components of rehabilitation projects.

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So 24

SOCIAL WELFARE ACTIVITIES OF LEPROSY PATIENTS FOR LAST 23 YEARS AT KUSHT SEVA SADAN, AGRA

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Kusht Seva Sadan (KSS) in the vicinity of Taj Mahal is one of the oldest Leprasoriums in India (founded in 1861). Leprosy Patients Welfare Society (LPWS), a N.G.O., is functioning for the welfare of Leprosy patients for the last 23 years. More than 60 (sixty) thousand leprosy patients have been benefited through L.P.W.S. during 23 years at K.S.S. where they got free boarding, lodging, during their short or long term treatment.

During this period, Health Education Activities have been undertaken by L.P.W.S. with an aim to create Awareness about early signs and other aspects of leprosy by organising several meetings and functions. The L.P.W.S. has widely spread the message to the people from all walks of life that leprosy is a curable disease using MDT and if detected and treated at early stage, deformities and disabilities are prevented. Such efforts of the L.P.W.S. have resulted in favourably changing the attitudes, practices and behaviour of the people towards leprosy.

The L.P.W.S. has also helped patients having reactions, bad ulcers and complications. Those who needed reconstructive surgery, arrangments were made at established leprosy hospitals in the country where facilities for reconstructive surgery are available. L.P.W.S. also helped cured leprosy patients for getting respectable, social and economic rehabilitation. The detailed activities undertaken and future perspectives will be presented and discussed.

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So 118

COMMUNITY HEALTH WORKERS IN LEPROSY ELIMINATION CAMPAIGN

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Recent strategy of Leprosy Elimination Campaign (LEG) has been employed widely in leprosy control programmes. Various categories of personnel are being utilised for this activity. We present our experience in Bihar in utilising the services of Community Health Workers. A total of 80 Community Health Workers belonging to a NGO in Nalanda district, Bihar, India were given orientation training on screening of population for signs of leprosy. This NGO covered a population of 55,000 in 54 villages. Propaganda was carried out for one day followed by a search programme (survey) for one day. These workers detected 50 new cases of leprosy and 50% of them were Multi Bacillary cases. The cost of detection per patient was Rupees 280 only. If a larger area is covered, the cost would be less. This clearly indicates that different categories of health workers could be successfully utilised for LEC.

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So 120

ROLE OF TRAINED HEALTH WORKERS AND COMUNITY PARTICIPATION IN LEPROSY ELIMINATION CAMPAIGN

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Leprosy is generally considered not just as a disease but a curse. This disease has been shrouded in myths and mysteries causing leprosy cases to untold sufferings, physical, mental as well as social. Recent developments about the disease and the introduction of modern treatment through MDT have caused a definite shift in the attitude towards leprosy cases. The magnitude of the disease is tremendous in some countries of Asia, Africa and Latin America. About 5,60,000 new cases are detected annually worldwide and over 70% of them arise from India alone. Today, leprosy is no longer treated as a dreaded disease. It is definitely curable and no leprosy-affected person has to face the problem of any deformity if diagnosed and treated in time. Therefore, the key to success of any leprosy elimination programme is the early detection of the hidden disease. Since the disease is attached to social stigma, the success lies in community participation in creating better awareness leading to voluntary reporting of the disease. Inspite of having such a heavy load of leprosy in India, there is a dearth of proper trained health workers. Health workers both at the community level as well as those associated with existing health infrastructure need appropriate orientation and training towards the disease elimination. It has also been observed that most of the leprosy patients come from under-privileged community.

GASP-PLAN, a NGO has made a strategic survey in the slums of Govindpuri, Sangam Vihar and Badarpur in South Deihi. It is promoting a three pronged strategy, i.e. LEG, SAPEL and availability of MDT towards elimination of the disease in the area. Leprosy is to be eliminated as a public health problem through active participation of the community and the trained motivated health providers.

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SOCIAL INTERVENTION MAKING A POSITIVE IMPACT IN A LIFE DISTURBANCE SITUATION OF A WOMAN WITH LEPROSY

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Leprosy perhaps is the only disease, which under the present law provides the grounds for spouses to insist on separation (Muslim Marriage Act 1939, Special Marriage Act 1955). The gender bias is reflected in the fact that men diagnosed with leprosy in India suffer fewer negative reactions as compared to women came as a welcome surprise when they do happen. Involvement of health professionals at all levels through interventions like counselling at individuals/ family levels coupled with health education and where required providing legal assistance can turn the situation in favour of the woman. A case report where team efforts resulted in making a positive difference in the life disturbance situation of a woman is reported. In the paper we describe our efforts which resulted in making a positive difference in the life of one such woman.

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So 146

LEPROSY IN THE NEW MILLENNIUM IN PERSPECTIVE OF EDUCATED YOUTH

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Second half of the 20th century changed the entire face of leprosy problems prevailing in our country for centuries. Advances in the chemotherapy augmented rapid decline in prevalence rate of leprosy. Prospective elimination of leprosy, in the very beginning of new millennium, has ensconced leprosy on the verge of integration into General Health System (GHS). The success of such operational transmutation of leprosy will mainly depend on attitude of society, and youth in particular.

This paper presents the study, undertaken to understand the state of readiness of educated youth to accept leprosy as a common health problem. The study, by means of interviews, was conducted among 1185 youths, from three places in Maharashtra, a progressive state of India, with varying leprosy endemicity, namely Mumbai, Raigad and Wardha.

Level of knowledge among this group is satisfactory. However, knowledge pertaining to infectivity and transmission is poor. 75% of respondents felt that the problem of leprosy is on the rise. While 69% opposed the isolation of leprosy patients, 60% refused to have conjugal relationship with a leprosy spouse. Similarly 57% advocated separate hospital for leprosy.

In the context of leprosy services and expertise, only 11% of respondents believe that doctor at GHS can diagnose leprosy correctly. Moreover, 69% are not aware that treatment on leprosy is available at GHS. Similarly, as low as 12% youth prefer to take leprosy treatment from GHS. 59% would even prefer leprosy hospitals for this purpose.

Much depends on new generation for success of integrated programme. Unfortunately their attitude seems to thwart the prospects of the progremme. It can be inferred that low prevalence of leprosy in recent years that has made leprosy uncommon problem for youth only to increase heedlessness among them. Negative attitude of youth towards leprosy calls for immediate corrective measures to rejuvenate health education activities to disseminate scientific knowledge about leprosy & bring about positive change among this group to accept leprosy as a common health problem.The authors caution that if corrective steps are not taken up, the new millennium will face macabre state of social problems related to leprosy.

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So 185

ROLE OF NGOS IN OVERCOMING THE STIGMA RELATED TO LEPROSY

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Leprosy is the oldest disease known to mankind. It is different from others disease that it affects the person totally, i.e. his health, look, self-esteem, job, family, his position in the society, etc. It is a major public health problem in India carrying 58% of global patient load with a prevalence rate of 5.9/ 10000 (WHO Sept. 99). But it is encouraging that the disease has shown a declining trend first time in 1987 and the World Health Assembly has taken a resolution to eliminate it. So the concerted effort of all concerned can help in overcoming the hurdles in controlling leprosy.

The stigma related to leprosy is the main obstacle to its efficient elimination. The fear of rejection by the family & society may cause more stress than the disease itself and may lead to hidden cases.

NGOs have been playing a significant role in the field of leprosy and in India there is co-operation and collaboration with Government but still there is a long way to go.

It has been felt that the stigma related to leprosy is due to the deformities it causes and this can be overcome by educating the people through effective IEC and by providing them the necessary informations, i.e. the disease, its transmission, treatment and rehabilitation facilities available and removing myths and misconceptions. We felt questions and answers from the community should be encouraged in effective designing of the messages to be communicated. Working with the community, we realized that no programm can succeed without community participation. Health facilities can help but it is the community that has to take the initiative in eliminating the disease. NGOs should try to create a leprosy friendly environment where affected people can come forward and seek voluntary help.

CASP-PLAN Delhi, an NGO, made a survey in Urban Slums, Sangam Vihar, Badarpur and Govindpuri and trained community health guides, Social workers and doctors on communication and early case detection of leprosy and has plans to carry forward the activities further.

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EFFECTIVE SPONSORSHIP FOR SOCIAL ACCEPTANCE OF CHILDREN IN THE SHADOW OF LEPROSY

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Leprosy has been considered primarily as a medical problem. Therefore, all Government efforts are rightly focussed on the early detection and treatment. However, experience has taught us leprosy is more of a social problem resulting in stigmatization, isolation and loss of dignity. This affects not only the patients but also their families. Therefore, while strengthening the medical programmes it is essential that attention should be focussed on issues like creating awareness, provision of counselling to the person affected as well as the family and orientation for preventing disability and dehabilitation.

The recent campaign conducted by Government of India has revealed that 18% of the newly affected cases are children below the age of 16; therefore if these children are not protected from stigma and isolation, the future of these children will be in jeopardy.

Number of social work procedures are in vogue in dealing with socio-medical issues like children in the shadow of H.I.V aids, cancer, leprosy, etc. Among these methods, sponsorship has been found to be a very effective method of dealing with such issues like leprosy. This paper tries to analyse the situation and indicates how sponsorship can be an effective tool in preventing dehabilitation/isolation and provides for utilizing techniques like case work counselling and appropriate communication.

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THE MISTREATMENT UNDER THE JAPANESE GOVERNMENT'S COMPULSORY HANSEN'S DISEASE ISOLATION POLICY

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The compulsory isolation policy of Japan was established in 1907, when Leprosy Prevention Law was enacted. Most of patients were compelled to be isolated to the sanatoriums (leprosariums), and to spend the life there by this law. Though its scientific grounds were scarce and it disregarded human rights, this law has been kept even after the development of dapsone for prejudices of society and medical authorities. Finally the law was repealed in 1996, in the result of a tenacious movement by the sanatorium residents (they were already cured, so they are now to be called not patients but sanatorium residents). However, they were forced a difficult situation over physical, mental, social and economical aspects, that is, the whole life, and such a difficult situation still has little been clarified by now. So in this study we try to clarify the situation in which the sanatorium residents in Japan have been put by the government s isolation policy. A detailed investigation by the visit interview method was done from 1997 to 1999 for all residents (1394 people) of the three national sanatoriums and the answer was obtained from 818 people (64%).

Fifty four percent of the sanatorium residents recognize that they were hospitalized compulsorily . 36% people of male had vasectomies. All men had to have vasectomies before they got married at one sanatorium. Twelve percent people of female had abortions. Almost all cases are regarded as compulsory on substance. There was no case of birth in sanatoriums, so it is thought that persistent eugenics policy for people with Hansen s disease have been done. Almost all members of sanatorium residents have experienced patients work. Patients work was not for rehabilitation but for maintenance of sanatoriums; it was applied compulsory and the tendency was seen that the more work people did, the more trouble was caused in their hands.

It is thought that a lot of human rights have been violated under the isolation policy in Japan. It is necessary that such history will be the significant lesson of the ideal way of the medical treatment including infectious disease policy in the future.

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So 377

THE TEXTURE OF OUR SOULS : TRANSFORMING THE SOCIAL IMAGE OF LEPROSY

Anwei Skinsnes Law, USA

More than 100 books and thousands of poems have been written by people who have personally faced the challenges of leprosy. Songs have been written and music has been composed. These books, poems and songs reflect deep emotional pain but, at the same time, present inspiring images of dignity and strength. As such, they are a tremendous, largely untapped, resource, and represent a powerful tool with which to change the social image of leprosy while, at the same time, providing an important commentary on the long-lasting consequences of prejudice, discrimination and injustice.

I have sometimes clasped in my arms the trees of the forest, praying God to animate them and give me a friend. Guascoz, France, 1803

My heart and head were full of the mystery of human existence. Especially in thinking of the friends gone before an inexpressible sadness came over me.... Shrill, shrill, the crickets chirp and

call, and from my heart the slow tears fall. Honami Nagata, poet and author, Japan

A man can survive a cataclysm; suffer the loss of his nearest and dearest; see the whole pattern of his life smashed to pieces, and yet remain basically unchanged; the inner texture of his soul untouched. Peter Greave, author of four books, England

There is a communion in everything related to nature, beginning with the waking of the birds in the melodious and harmonious song in the almond trees, spreading happiness in our spirit at times of such great need. Antonio Borges, Jr., author, Brazil

I stopped to watch the baby chickens feed a while, And as they scratched in search of worms,

My gloom was gone,

And I

Found I could smile! Hayashi, Japan

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So 378

FREEING OURSELVES OF PREJUDICE : LANGUAGE FORMS OPINIONS

Anwei Skinsnes Law, USA

Language forms opinions

The strong negative associations with the term leprosy and thoughtless use of the derogatory word leper have resulted in many people advocating that the name of the disease be changed to Hansen s Disease . However, the issue of terminology goes far beyond a preference for the term Hansen s Disease or leprosy and their equivalents in different languages. The images, language and labels used in association with leprosy or Hansen s Disease have the power to either destroy a person s life or reaffirm their humanity.

Every culture has language that is hurtful and language that promotes dignity. To promote self-confidence in those individuals personally faced with the challenges of leprosy and to change the traditional social image of the disease, it is imperative to replace hurtful language with language that recognizes a person as an individual separate from the disease and focuses on ability rather than disability.

When I look back at my past, my soul is beckoned to the poems I wrote of my father. There are times when I think it would be more natural for me to write about my life as a leprosy sufferer, but my attitude of mind as a poet is inclined more to write about my existence as a human being. Haruko Tsuda, Japan

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LOCAL PARTICIPATION IN URBAN LEPROSY ERADICATION PROGRAMME

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Community Participation is one of the most popular terms of the era specially when speaking about people oriented programmes. The success of any programme is attributed to community participation. Community participation in leprosy eradication programme is still restricted to community leaders or few volunteers.

Involving organized groups in the community for leprosy control activities is a novel idea adopted in Salem urban, Tamilnadu, India. The organization covers a population of 5,50,000. The area is divided into 11 sectors and has 33 drug delivery points. Registered and unregistered organizations in the project area (community) are roped in, motivated, trained and employed for case detection, completion of treatment and preventive education. During the year 1999-2000, a total of 825 leprosy new patients are registered for treatment. Treatment compliance is more than 95%.

The experience of St.Mary s, Salem in collaborating with the service oriented groups and strategies employed in enlisting their co-operation will be discussed in detail.

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TRIALOGUE - A STRATEGY FOR COMMUNITY/FAMILY BASED REHABILITATION

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For Community Based Rehabilitation (CBR), it is essential that community & family is educated about the scientific facts of leprosy and convinced about curablity. Uprooting perceived fear of infectivity, myths & misconception is a precondition for raising leprosy affected persons. Counseling through trialogue has been tried for the same purpose. 8 issues of ostracisation and 4 issues of social restriction were resolved successfully, through TRIALOGUE.

The issues were resolved in POD care & concern camps. Many sittings and follow up was required to reach the goal. Individual case was of its own kind, requiring same strategy & approach i.e. TRIALOGUE.

Cases which were resolved belong to rural area of different districts. This effort not only resolved the problem of ostracisation but also prevented future ostracisation & restrictions on social services to Leprosy Affected Persons (LAP) was also put to an end .

TRIALOGUE is a strategy which aims to changing community attitudes and behaviour through role models, active participation in caring for leprosy disabled as well as open and honest discussion about fears concerns, prejudices and problems. This is an interactive method between the key playerspatients, providers and people around - all of whom are on an equal footing.

In POD CARE & CONCERN CAMPS many myths & misconceptions about leprosy get resolved automatically because of services and action oriented activities. During camp all three stake holders

i.e. patients, providers of services and people around (PPP), are actively associated to surface the social issues and discuss then openly. KAP changes through TRIALOGUE have been sustainable. Decisions arrived at in this TRIALOGUE situation is a concensus decision leading to resolution of the issues.

The strategy is being applied in the entire state gradually and health functionaries have been identified to function as facilitators.

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So 105

A STUDY OF BEHAVIOURIAL CHANGES IN SCHOOL GOING HEALTHY CHILDREN OF LEPROSY PARENTS

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Leprosy is being considered a social stigma & God s curse rather then a disease. Not only theleprosy parents but their children are also discriminated in our society in all spheres of life. 77 schoolgoing healthy children having one or both leprosy parents were examined to study the behavioural changes according to child score B, i.e. children behaviour questionnaire prepared by child psychologist. These children of leprosy parents were being admitted in charitable school cum ashrams which was providing boarding & lodging facilities to the children which helps them not only to study in a good environment but also to train them in vocational courses. These school cum ashrams had helped to avoid social stigma attached to these children of being having one or both leprosy parents. All these children were in age group of 5-15 yrs. 58 children were having non Punjabi parents & 19 having Punjabi parents. None of these children was having any signs & symptoms of leprosy nor any child showed any significant behavioural changes as recorded on children s behaviour questionnaire. So these charitable boarding & lodging schools for children of leprosy parents is the need of the hour in our society to help these children to become responsible citizens without any social stigma of their parents disease which requires initiative from the dermatologists with active participation of social organisations.

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ASSESSMENT OF IMPACT OF SER ASSISTANCE ON THE SOCIO-ECONOMIC STANDARDS OF LEPROSY AFFECTED

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Socio economic rehabilitation programme is implemented by LEPRA India in a project covering two tribal districts in Orissa since three years. The approach is holistic, evolutionary and participatory. Appropriate systems are devised for identification of clients, assessment of needs, economic assistance and support through follow up to enable the clients to reestablish normal family and social relationships. The approach involves family and local community in all stages of the programme.

150 clients were provided assistance to take up income generating schemes of their choice; the State Govern-

ment has been a major player in the scheme of assistance.

The impact of SER assistance on the family and socio-economic situation of the clients has been assessed by administering an interview schedule to 150 beneficiaries.

The results are analyzed and the findings are discussed with special reference to the differences in impact in extent of disabilities, gender issues, rehabilitation and location of the clients.

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So 153

REASONS FOR BEGGING BY LEPROSY COLONY-MATES AND WHY THEY LEFT HOME

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Objectives : To find out the reason for begging and causes for resorting to colony life.

Design : Cross-sectional study, by using questionnaire.

Setting : 4 leprosy colonies in Vizianagaram district of Andhra Pradesh were taken for study.

Participants : Leprosy affected persons (RFT) living in these colonies.

Main out-come Measures : 118 heads of families were interviewed, in June 1998.

Results : For 73% of them, having deformities, begging became the last resort. 15% of the total interviewed, joined colonies due to rejection by families.

Conclusion : Deformity and rejection by family lead most of them to begging. All of them are interested in their children s future, and want assistance for their education and vocational training. If alternative source of income is provided, with guarantee, 15% of them are willing to stop begging.

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So 155

FACTORS INFLUENCING REGULARITY OF TREATMENT OF LEPROSY PATIENTS

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In order to understand the contributing factors responsible for treatment compliance or otherwise in leprosy patients, 288 patients attending the OPD of central JALMA Institute for Leprosy, Agra were selected for this study. Of these, 74 patients were drop-outs, 121 patients were irregular and remaining 93 patients were regular in seeking their treatment.

These patients were interrogated in-depth to inquire about their demographic profile, SES status, their knowledge about disease & its associated deformities, treatment and its curative aspect and other related factors such as nature of occupation, distance, timings, other sicknesses, family responsibilities & so on; so that the relevent factors can be identified which act as the barrier in seeking regular treatment.The details of the findings will be discussed at the time of presentation.

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COMMUITY PERCEPTIONS AND THEIR INFLUENCE ON DEHABILITATION OF PERSONS AFFECTED BY LEPROSY

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Leprosy not only affects the body; it also disrupts patient s socio-economic & cultural balance and leads a patient into a state of Dehabilitation . Dehabilitation is a reduction in the social function of the individual, which is reflected in the overall quality of life, attitudes and actions. Societal factors play an important role in determining or preventing dehabilitation of people affected by leprosy.

This study analyzed the perceptions and practices of the community regarding leprosy and persons affected by leprosy and their influence on dehabilitation of patients. 50 leprosy-affected patients were interviewed based on a questionnaire (55 questions) that covered family relationships, vocational conditions, social interactions & self-esteem of the patients. For each patient, two other members were interviewed (50 questions) from among their family, relatives, work place colleagues or society members. The study was conducted in the HYLEP urban control project of LEPRA India in Hyderabad. Half of the respondents were from a high endemic area and half from a low endemic area.

In the high endemic area, the average dehabilitation score for vocational interactions was highest indicating that the patients were well accepted in their work places. Next in descending order was family relationship; self-esteem and acceptance in society was the lowest score. In the study of dehabilitation of society, it was found that the family members had the highest score, followed by work colleagues, relatives and other society members. This shows that family members have the highest acceptance of the patients compared to the other three groups. The dehabilitation score of patients and society from the low endemic area reveal almost identical figures as the high endemic area with only a marginal increase in the average values. Further recommendations based on the study will be discussed.

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FACTORS INFLUENCING DISCONTINUATION OF TREATMENT AMONG PERSONS AFFECTED BY LEPROSY IN EASTERN NEPAL

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In preventing patients from early discontinuation of treatment, many programmes invest in improving the doctor-patient relationship, improving the patient s knowledge about the disease and its treatrnent and creating informed-consent . These approaches assume that patients take a rational decision to continue or not with treatment and that problems faced by the patient can be solved. Not only these are important issues, but also the whole context, the patient s life, culture, and perceived structural barriers are important. On basis of this perspective a study was conducted to investigate the main reasons why some patients continued treatment and other did not. The study conducted was qualitative and in-depth interviews were used (n=76). The patients understanding of their disease and experience with treatment as well as their diverse situations were investigated.

The findings clearly demonstrate that the social context was important in how people looked at the person affected by leprosy. The person s ritual, economical and political status was of influence in how the disease was experienced by the person affected by leprosy and in how the family and community members acted towards this person. Other important factors which influenced the decision to continue or not with treatment were the perceived quality of care of. the leprosy services delivered at the HPs, the side effects experienced, the presence of visible symptoms and deformities, fear of social repercussions and a different notion of cure. To cure the disease leprosy, a patient needs to be able to finish his/her treatment. This study shows that decisions to discontinue treatment must be regarded as a patient s attempt to gain control over his/her life; whereby this gaining of control can be more important to the individual than achieving medical cure. The presentation will focus on some of the results and especially on the effect of interpersonal relationships and will show how persons affected by leprosy gain control over their lives and thus stopped medication.

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PHYCHO-SOCIAL ASPECTS OF LEPROSY

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In 1991, more than 400 Nepali leprosy patients were interviewed using a WHO self reporting questionnaire designed to detect non-psychotic disorders. The questionnaire was supplemented with questions about the patient s family and social situation. The data showed a low but significant level of mental health problems among leprosy patients (80/411, 22%) and identified significant factors predisposing patients to psychological stress (poor family acceptance) as well factors reducing the risk of mental illness (literacy, admission to hospital). The same questionnaire was used in interviews with leprosy patients in 2000, and the results compared with the earlier cohort.

Since leprosy health care includes care of possible psychological and social problems caused by the stigma associated with leprosy, it is important to measure the extent of these problems. Improved individual and social acceptance of leprosy has been posited to be the result of the newly perceived curability of leprosy and the decline in deformity in the past 10 years since the introduction of multi-drug therapy (MDT). However this improvement has not been documented in any quantitative manner. The comparison of data collected from two cohorts of patients nearly 10 years apart will provide important information on the trends in leprosy patients mental health and social acceptance..

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COMMUNITY PARTICIPATION IN LEPROSY ELIMINATION

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Community is a term applied to society and social groups inhabiting a particular area and acting together in the chief concern of their lives. The community consists of groups of people living in harmony and interdependence. Therefore The Community plays a pivotal role in the scenario of leprosy elimination and rehabilitation of the victims of the disease, leprosy.

In order to ensure their participation, the NGOs and Govt. authorities must bring about an awareness of leprosy at every level and motivate the community to go hand in hand with the efforts of the NGOs and Govt. authorities to tackle the disease and to bring under control the prevalence of the disease and minimize the trauma that follows alongside.

What steps are taken towards community education? Health education and social rehabilitation aspects must be popularized. The community must be awakened to its responsibility that elimination of the disease and rehabilitation of its victims lies solely with them.This in turn will elevate the social status of the leprosy patients in the community.

Support for Community Action for Leprosy Elimination (SCALE) is one such community based project launched to motivate and mobilize community action and utilize the community resources for active support of leprosy elimination.

SCALE aims at harnessing community volunteer groups to assist leprosy work. This project initiates active health education programmes on leprosy to the general public about every aspect of the disease. Skin camps are organised to detect hidden costs and to bring them out for medical care and surgical assistance. This project also promotes active involvement in welfare and rehabilitation activities in order to pave the way for quicker social assimilation. Ideas and suggestions arising from the community participation are periodically exchanged with the NGOs and Govt. authorities through seminars which help update their plan of action.

In short, the involvement of the community is of such integral importance that from the stages of detection of the cases, treatment and care to rehabilitation the communitys active participation plays an important function which no other body can assume.

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NON-CONVENTIONAL METHODS OF HEALTH EDUCATION

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The non-conventional methods of health education bring novelty both to the leprosy workers and the audience which has been experienced at the Balarampur Control Unit of the Gandhi Memorial Leprosy Foundation in West Bengal. The methods were puppet-show, street play and Kustha-Samkirtan . The stories were based on the incidents which took place locally, played by the leprosy workers in local dialects. There is scope to change the stories, characters, dialogue while the central theme, the message on leprosy remains the same.

Introduction of non-conventional methods of health education along with routine activities has encouraged early case reporting, treatment compliance and in·volvement of the social leadership in anti-leprosy activities.

An analysis of data collected for last 8 years (1992 - 1999) produces encouraging outcome. Total 386 programmes were conducted in 287 villages with an average audience of 450. The effects include on spot reporting 241 persons with suspicious lesions. Total 322 patients were reported and registered including cases referred by teachers, community leaders and family members.It also prepared grounds to solve unfavourable issues.

The above findings suggest that non-conventional methods have potential contribution to create mass-awareness in leprosy and to change behavioural pattern as well, especially in the rural area.

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EFFECTIVENESS OF IEC INTERVENTION IN SPECIAL LEPROSY CAMPAIGN IN AN URBAN AREA OF ORISSA

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Modified leprosy campaigns were conducted in Orissa with the components of active search and confirmation involving General Health Care staff. One such modified leprosy elimination campaign (MLEC) was conducted with the strategy of Voluntary Report Centre approach in Orissa State three months after a similar exercise.

LEPRA India established an IEC and POD unit in Bhubaneshwar urban area to strengthen the services in Bhubaneshwar leprosy eradication unit in the areas of Health Education and POD. Voluntary reporting centre approach was implemented under the guidelines of Government of India with necessary pre-requisite IEC activities in July, 2000. IEC activities included methods of personal communication and information campaign using mass media. The content of the message concentrated on improving voluntary reporting of ases to existing health facility treating leprosy. All people who have attended the voluntary reporting cases were interviewed to know the source of information to assess the effectiveness of IEC campaign.

151 people reported at voluntary reporting centres with suspected signs of leprosy. 82 patients were confirmed with active signs of leprosy. It was observed in the analysis that 8 people reached voluntary reporting centres merely by seeing the directive signboards and banners. Effectiveness of these intervention methods of IEC activities used and their reach in urban and semi urban areas of Bhubaneshwar city were discussed in this presentation.

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PERCEPTION AND HEALTH BEHAVIOUR OF LEPROSY AFFECTED MIGRANT PEOPLE - AN OPERATIONAL RESEARCH

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Secunderabad

An urban leprosy project was established in 1989 in Hyderabad city of Andhra Pradesh with SET strategy under NLEP guidelines. The project covers a population of 1,98,487 in the peripheral wards of Hyderabad city. The study area has 10% migrants among the general population. The migrant population is distributed in small groups. Many people from neighbouring villages migrated in groups with family members seeking their livelihood. These people along with their families settled in clusters of huts in the border of project area. The health behaviour among these migrant groups is different from resident urban population. Study was conducted to understand the perception and social reaction among urban and migrant population towards leprosy. Data was collected through in depth interviews through qualitative interview techniques. The findings are used to formulate innovate strategies to cover these population. The study findings and strategy for programme coverage are discussed.

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KAP AMONG GENERAL PUBLIC AND SERVICE PROVIDERS AND PROSPECTS OF LEPROSY INTEGRATION

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The Y2K has not witnessed, immensely promulgated leprosy elimination. The world will enter the new millennium, in a month s time, encumbered with reasonably high prevalence of leprosy and static rate of New Case Detection (NCD) in various parts of endemic regions. Yet, pronouncement of Integration of Leprosy into General Health System (GHS) appears decisive. Positive attitude of society & beneficiaries and preparedness of service providers are pre-eminent determinants to success of Leprosy Eradication Programme through GHS. In this contest, KAP Studies were undertaken among general public and GHS service providers (GHS-SP) to gauge the prospects of Leprosy Integration Programme in Raigad District of Maharashtra State.

The study observed satisfactory level of leprosy knowledge among 996 lay respondents and 488 GHS-SP. The least confidence in GHS in regard with leprosy expertise is shown by general public (4%). Only 12% prefer to taken treatment from GHS. This can be attributed to the inferior quality of services people experience at GHS. As many as 77% are against conjugal relationship with leprosy spouse and 73% advocating isolation of leprosy patients in this hi-tech cyber-age.

While 75% of GHS-SP respondents showed no reservation for Leprosy Integration Programme, 67% opined that such operational transmutation will help eliminate social stigma attached to leprosy. However, they seem equally divided over their view about the need to continuing NELP to hasten the process of Leprosy Eradication. Although 73% of GHS-SP respondents were found to acquire correct knowledge of suspecting leprosy, 53% do not know right diagnostic signs. Similarly, knowledge in view of leprosy complication is observed far below satisfactory level.

The paper also examines the impact of level of KAP among general public and GHS-SP on pattern of New Case Detection (NCD). The dependency on active survey to detect over half of the new cases is increased by 30%. in post MDT period. GHS contribution in NCD has leapt to double (from 8% to 16% of total NCD) against a steep fall in voluntary reporting by 44%.

Continued on next page The authors review the areas needing immediate attention and discuss the prospects of Leprosy Integration Programme. However, the authors believe that the time is not yet congruous for integrating leprosy into GHS. at least in the regions with alarmingly high PR & NCDR and technically unprepared GHS-SP in terms of leprosy espertise. It is inevitable at this juncture that, to achieve desired results of integrated programme. priority should be given to eliminating dependency on leprosy institutes and to restoring faith in GHS for leprosy.

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HEALTH EDUCATION FOR LEPROSY IN RURAL AREA

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I am M.D. Shaikh, Leprosy Assistant working in NLEP in Gujarat State. I want to explain some experiences about Health Education in Leprosy. Health Education plays an important role in the control of leprosy. It should be directed towards the general public, especially receptive sections such as students, school children, school teachers, also medical students and physicians, paramedical workers and the leprosy patient and his family.

Most of the public live in villages. They have not enough education about leprosy Those people have blind beliefs about leprosy disease. As per my field experiences, people believe that leprosy means Man who has lost his hand, feet and fingers, depresed nose, lion face or a claw hand . People do not know early signs and symptoms of leprosy - even educated people are ignorant about leprosy. Due to social stigma, people are not taking interest to work in this field.

Health education is the most important to detect early leprosy cases. In rural areas people have some blinds beliefs such as:

1) Leprosy is an incurable disease; 2) Leprosy is a heriditary disease.

First of all, we should remove these beliefs by health education - flip book in local languages, charts and posters are very useful for wide spread health education about leprosy During house to house survey, flip book is very useful, like AN ATLAS OF LEPROSY patches on different parts of body where loss of hair, different colour from original skin colours, nodular thikening of earlobes, loss of eyebrow -this kind of photo pictures are very effective with rural people. By seeing this book, hidden cases themselves come out for treatment.

Those people who have no knowledge about leprosy because they live in tribal intenal areas, sometimes they cannot take early treatment and become victims of deformities.

Now-a-days our government has started M.L.E.C. and in this programme, we are giving broad health education in rural areas. We have finished two M.L.E.C. programmes in Gujarat State by general health staff.

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MAKING HEALTH EDUCATION EFFORTS RELEVANT : THE KARIGIRI APPROACH TO COMMUNITY TRAINING

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With integration of leprosy services with general health care, there was a need for senior field personnel from the original leprosy programme to be retrained in key areas of general health, so as to make them equivalent to their counter-parts in the public health sector. This paper presents our experiences and efficacy in undertaking a training course in Health Education for Senior Non-Medical Supervisors in the Government of Tamil Nadu.

A total of 35 participants were trained in two batches, each for 2 months duration from April 1999 to July 1999 at SLR &:TC, Karigiri. It was decided to use the strategy of employing only active learning methods so that they would be involved in Learning by Doing . The curriculum was designed partly as community-oriented and partly community-based. Modern methodologies tailor-made to suit the needs of the groups were used. Dynamic innovations based on the current situation in specific groups are incorporated. Finally, the programme drew from the experiences of individual members, utilizing peer to peer teaching and learning strategies to the fullest. After carefully considering individual differences of the participants, they were divided into 4 groups. Two nearby villages were geographically divided into four areas for implementation of Health Education activity. Participants were motivated to establish good rapport with the community, and were required to conduct an initial survey, to establish lacunae in the health situation as well as establish the level of knowledge among the villagers by a pre-test. Four key areas were identified by the participants such as Maternal and Child Health, Polio, Environmental Pollution, etc. The topic was then utilized both to learn about, share their newly-learned knowledge with the other three groups as a trial teaching process, impart this information to the community, and finally monitor the effectiveness of their health education effort by a post-test among the villagers.

The level of knowledge of the villagers for all groups taken together was 27% in the pre-test and 72% in the post-test. Improvement in specific topics was a minimum of 32% and maximum of 71%.

Further details and experiences will be discussed and presented in the paper.

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IMPACT OF IEC IN URBAN LEPROSY CONTROL IN CHENNAI

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I.E.C. continues to be the strongest instrument in case detection at Gremaltes Hospital in Chennai. Gremaltes caters to a population of twenty four lakhs for the period of three decades. Out of the 56,932 detected cases so far, 32.13% is by voluntary reporting.

This has been achieved by intensive systematic I.E.C. covering the project area of seventy nine corporation divisions. Mass group and individual approach were used by trained health educators and other health workers.

Comparison of various modes of surveys in case detection versus voluntary reporting is discussed in detail in this presentation.

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METHOD AND EFFECT OF HEALTH EDUCATION ON LEPROSY IN THE NATIONAL AREA OF SICHUAN PROVINCE IN CHINA

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Health education on leprosy are carried out in the Liangshan national area of Sichuan Province, the knowledge of leprosy are popularized, good effect is got in discovering more patients and increasing the knowledge leprosy grasped by the civil servants.

Method: The government attend the workshop to training the directors of the town and the sanitation house as well as epidemic doctors. News media and public health organization carry out health education on leprosy by all kinds of methods. Special organizations collect the clues reported by the barefoot doctors and the mass, assign experts to detenninate the diagnosis. Health education covers 17 counties, 601 townships, more than 3709 villages. 59 short training classes are held, 4707 cadres of counties, townships and villages and health workers attend the training, 225 clues are reported right now, and 47 are determinated as leprosy patients by bacterial and histological examination. 134 cases are discovered in the preecture that year which is 47 cases more than the year before (54% more). The knowledge of leprosy grasped by health workers and the mass is increased. It demonstrates that it is necessary for the government to attend the health education on leprosy in the national area, which can discover the hidden patients in the community, and teach a good lesson on leprosy to the whole society, push forward the work of elimination of leprosy.

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AWARENESS ABOUT LEPROSY IN SUNSARI DISTRICT OF NEPAL

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Nepal is one of the countries with high prevalence of leprosy and in general the prevalence of the disease is relatively higher in the Terai compared to the Hills. In line with the objective set by WHO for elimination of leprosy, a Nationwide Leprosy Elimination Campaign (NLEC) was undertaken during August 1998 to February 1999 under the co-ordination of the Leprosy Control Division, Department of Health Services, HMG, Nepal. One of the objectives of this campaign was to increase community awareness. In the present study, we analyzed the knowledge of leprosy, leprosy elimination program and the impact of the media on such awareness in the population of Sunsari District, Nepal on national immunization day program (21st November 1999). A total of 1647 respondents were interviewed. Out of which 60% were female and 74% were in the age group of 20-40 years. Agricultural workers constituted 58%. 31.6% were illiterates. Approximately 60% of the respondents knew the cause and symptoms of leprosy. Leprosy is curable was felt by 81.8% and 95% thought that in suspicion of disease it is necessary to go to hospital for treatment. Although, 75% of the respondents knew that drugs for leprosy are available free of cost but the goal of elimination by 2000 AD was understood by only 47% of respondents.Radio was the single most effective means of providing information, education and communication about leprosy. The good response about leprosy knowledge in illiterates was comparable to others. A good knowledge may increase the attitude towards leprosy, case reporting, and motivation to be cured and decreases the deformity. So, intensification of health education is a must for achieving the goal.

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MASS AWARENESS THROUGH VILLAGE MEETING

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A simple formula for mass-awareness without any expense. In my strategy, every NMA will conduct one village meeting in every week. Hence, there will be 4 meetings in a month and 48 meetings in a year. If there are 50 NMAs in the district, the total village meetings will be 2,400 in a year. The total village under one district is less than 2000 in maximum cases.

If it is good, it can be tried in N.L.E.P.

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AWARENESS ABOUT LEPROSY IN SUNSARI DISTRICT OF NEPAL

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DISABILITY AND REHABILITATION - MASS AWARENESS THROUGH MEDIA

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The persons lacking normal functional ability due to the disease Leprosy are within the social jurisdiction but except a few, they are not in tune with the main-stream. They also equally become the victim of self - stigmatisation and the loss of psycho - social equilibrium stimulates these persons even to be hostile to the society and to curse their own fate.

Social participation of the disabled is a multifunctional and multi-sectoral approach. It includes social, psychological, educational, occupational, economic and medical measures aiming at social assimilation of the Leprosy disabled.

The power - lobby needs equally to be.aware regarding the dimension of the rehabilitation - problem and steps of solution. All these factors call for a planned change to influence the social attitude and media can contribute potentially to create a desired mass awareness level.

The coverage of rehabilitation services could broadly be incorporated by print, electronic and folk media. While print and electronic media have much influence on the literate and urban people, folk and non conventional methods have greater approach to the rural people.

In order to maintain the correct, integrated, uniform and comprehensive quality of communication, the media - persons should be oriented on the subject through a series of workshops organised all over the country. A syllabus could be worked out accordingly.

The respective programmes, persuations, contacts and organisational activities will be undertaken by the rehabilitation service agencies but in order to maintain the harmony, pace and parity, it is suggested that a co-ordinating agency should be there on national level.

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