Free Papers - Social Aspects

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Leprosy After Elimination: Putting Back Those

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While the drive towards a world without leprosy has made very significant progress, the focus on treating new cases has also had the effect of pushing a wider group of people whose lives have been negatively affected by leprosy further into the margins. This paper draws on long-term intensive fieldwork with a particular group of leprosy-affected people in Andhra Pradesh, South India, to address this issue in two key ways. Firstly, it analyses some of the problems faced despite—and, sometimes, because of—the elimination of leprosy by cured leprosy-affected people and their families. Secondly, it considers how we might address those problems in a world where leprosy is no longer a major health problem; not, as is usually the case, by assuming particular goals of rehabilitation, but via an ethnographic exploration of how those I worked with managed their everyday lives.

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Exploring Grassroots Leprosy Organisations

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Leprosy has been a scourge and a source of fear for thousands of years with social exclusion and disempowerment resulting for millions of people. This paper, based on my thesis, explores reasons for the recent emergence of grassroots leprosy organisations; whether leprosy-affected people can achieve social inclusion and empowerment through membership in such organisations; and to what extent are grassroots leprosy organisations accepted by international anti-leprosy organisations and is it possible to have meaningful alliances and partnerships between them? Through field visits to undertake case studies of two such organisations, ENAPAL in Ethiopia and HANDA in China, I was able to use a combination of methods of inquiry including semi-structured interviews and focus groups, along with participant observation. The paper brings together the case study information, research aims, ideological contexts, other academic works, and discusses the results that emerged. The results indicated that, firstly, the failure of welfare programmes plus the common experience of leprosy and subsequent human rights abuses have driven leprosy-affected people to join together in collective action; secondly, working with a participatory approach that attributes as much importance to process, i.e. a bottom-up model of working, as to results contributes significantly to the sense of belonging that membership in grassroots organisations has brought about; thirdly, meaningful alliances and partnerships are possible with some international anti-leprosy organisations but much depends on the organisational culture of each organisation; and fourthly, membership in grassroots leprosy organisations is achieving a measure of social inclusion and empowerment for the members. In conclusion, the research asserts that ENAPAL and HANDA arguably have as their membership some of the world’s most oppressed people. Yet, as constrained as they are, these people have shown that through the strength of collective action and solidarity they can be change-makers. During the research the work of Paulo Freire (1989) is recognised, in particular, his insistence that, with appropriate conscientisation, oppressed people must struggle for their own interests and not leave their fate to others. This paper affirms Freire’s claim, that the finest struggles with the best results are those fought by oppressed people themselves.

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Assessment of Stigma Against People Affected by Leprosy and Those with Other Disabilities in War - Affected States of Darfur

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In 2000, my predecessor conducted a KAP study in the population of West Darfur on Leprosy and Polio. 90 per cent of people interviewed recognized that they could not shake hands or share a meal with a person affected by leprosy, while this figure was 42 per cent for people affected by polio. A participation scale was used to assess perceived stigma. The interview was conducted using some parameters such as age, sex, marital status, level of participation restriction of people affected by Leprosy and other disabilities, members of the union of disabled. The study was conducted in the 3 capitals of Darfur States. We found that there was no direct relation between the result of participation restriction of people affected by leprosy in the community and their level of participation in the union of disabled. We think that the level of participation in the Union of Disabled found in Geneina which was the highest is due to three reasons: the union of disabled promises is built near the leprosy village of Geneina. The Geneina Union receives food for all from World Food Program (WFP). And finally, the Geneina Union is having a representative of people affected by leprosy in the governing board. It will be useful if we could develop a tool such as Participation scales to assess the level of participation of people affected by leprosy in a union of disabled. The intervention like community awareness should tackle the level where the restriction is found. Keywords: Stigma, Leprosy, Disabilities.
The Advisory Council of the Tavares de Macedo State Hospital: An Exercise in Citizenship and Democratization

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The Tavares de Macedo State Hospital (HETM in Portuguese) in the State of Rio de Janeiro is one of 33 Hansen's Disease (leprosy) colony hospitals in Brazil. In July 2007 the hospital had 192 beds, of which 120 were inactive. 72 beds were in use, distributed between five wards and four shelters. Of the latter, 80% were in use due to the particular social needs of the patients. Of a total of 47 patients admitted to the wards and requiring clinical treatment and/or nursing care, 46 were ex-carriers of Hansen's disease, the majority of whom presented clinical conditions unrelated to the disease. Only one patient was undergoing active treatment for the disease. The aim of prioritizing the health and social needs of the residents of this community - ex-carriers of Hansen's disease - was formative in the creation of the Advisory Council of the HETM. This initiative is the central strategy of the citizenship project undertaken by the Movement to Reintegrate People Affected by Hansen's disease (MORHAN in Portuguese). The objective of this project is to open up possibilities for the users of the services of the Tavares de Macedo State Hospital to be reintegrated into the community. The Management Council supports and oversees strategic planning in which users decide together about the purposes of the hospital and evaluates the attainment of defined objectives and aims. The council is the forum for intense discussion related to all areas of the hospital, including ambulatory, clinical, shelter and community services, with the goal of assuring quality and meeting the needs of the users of these services. Representatives of these users account for half the seats on the council, with the remaining places allocated to management and staff. This model, in which monitoring of the services offered to ex-carriers of Hansen's disease is undertaken by the users of these services, is one of the components of the movement towards democratization and citizenship, which is producing in a participatory way improvements in the quality and way of life of this community. The results of this process will be presented and discussed. Keywords: Colony Hospital, Leprosy, Hansen's Disease, Citizenship, Tavares Macedo. Advisory Council, MORHAN.

Integrated Care for Ex-Carriers of Hansen's Disease – A Challenge for a Colony Hospital

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An effective care policy for patients with Hansen's Disease (Leprosy) requires integrated care, which necessitates the creation of a system which guarantees integrated care for these patients. Negotiations and agreements with the municipality of Itaborai (Rio de Janeiro State, Brazil), for example, where two family health teams cover the residents of the area, a holdover from the policy of compulsory isolation, are fundamental for the redefinition of the Tavares Macedo State Hospital as a reference center for physical and social rehabilitation. The strategy suggested here for the delivery of integrated care to patients with Hansen's Disease resident in the vicinity of the hospital should be understood as a phase of transition away from an inadequate and inefficient mix of medical and social care. The spectrum of care, from the home visit by the family doctor to the defining of a solution for the social situation of each individual resident, needs to be concomitant with the adoption of effective management initiatives aimed at improving the quality of life for those suffering from sequelae of Hansen's Disease. The implementation of such an integrated care strategy for patients resident in the areas of former leper colonies or specialized hospitals will only be possible on the basis of a policy decision by State Department of Health, differential allocation of resources for medium and high complexity care and the adoption of an articulated network for health service referrals. In order to maintain and consolidate such an initiative the State will have the contribution of the Movement to Reintegrate People Affected by Hansen's Disease (MORHAN in Portuguese) in regulating the measures taken by the patients themselves, as well as technical support in defining the directions to be taken in regard to land ownership and the limits and possibilities for initiatives aimed at the rehabilitation of the citizens of this community. Keywords: Colony Hospital, Leprosy, Hansen's Disease, Tavares Macedo. Integrated Care, MORHAN.
World as One Family by Work Camp

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JIA was established in August 2004 to coordinate volunteer work camps in villages affected by leprosy (Hansen’s Disease, HD) in China. JIA stands for “Joy in Action” and is homophonic with the Chinese character “home” or “family.” From 1950’s, the Chinese government relocated people with HD to mountain areas (we call “village” and “villager” here). Till now, 617 villages still exist. Even though the disease of almost all villagers has been cured, many still cannot go back home because of the stigma. The villagers today suffer from the disabilities, poor medical treatment, poverty, and loneliness. JIA aims to alleviate their suffering through hosting work camps in their villages. Typically more than 20 volunteers live there together with the villagers and carrying out construction project. This action establishes personal relationships among the villagers and volunteers, and the people outside comes to realize that they do not need to be afraid of HD. Action exceeds thousands of words. In order to solve more problems that the villagers are suffering from, JIA set up Volunteer Team Network, that is: Legal Aid; Case Work; Information; Project Development; and Alumni Team. Now, our volunteers can often listen to villagers’ voice such as: “You are closer than my children”. Keywords: Volunteer Work Camp; Network; Home.

Stigma, the Main Challenge for the Implementation of the New WHO Strategy in Khartoum

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Despite the joint effort done by the National Leprosy Control and ILEP members in fighting leprosy, the result of the main indicators remains below the acceptable standards: Stigma affects all the components of Leprosy control e.g. the case finding with the grade 2 disabilities 16%; the case holding with a low completion despite the fact that 80% of patients are treated by a specialized, well trained and committed staff. A review of registers and patients cards combined with interviews of staff and patients on treatment have shown: That more than 45% of new cases come from outside Khartoum. When asked to go and follow their treatment in the nearest health facilities, most of them refuse to go back home. Some give even false addresses to prevent any initiatives of contact or defaulter tracing. Only few patients on MDT disclose their sickness to their family. Only one hospital admits leprosy patients with severe reactions. Because of stigma among health personnel, the effort to establish rehabilitative and reconstructive surgery has failed in the last five years. Fighting stigma against Leprosy should be the first priority of the Leprosy Control Program in Sudan, which should learn from the experience of HIV and Polio program. There is an urgent need for a hospital which will provide integrated rehabilitative and reconstructive surgery. Keywords: Stigma, WHO, Strategy.

Best Practices in the Socio-Economic Rehabilitation of Persons Affected by Leprosy and Other Marginalised People in Their Communities: Findings From Nine Evaluations in Bangladesh, India and Africa

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The present paper presents an overview of findings from the formal evaluation of 9 socio-economic rehabilitation programmes implemented by TLM in 4 countries in Africa, in Bangladesh and in India in the years 2002-2005. Bringing together the recommendations resulted in a description of best practices in the implementation of socio-economic rehabilitation programmes, derived from actual experiences in different contexts. The 9 programmes all focussed on supporting individual leprosy-affected beneficiaries or their families. Four projects also supported other marginalised clients. The usual interventions were micro-credit, housing and sponsoring of education for the children of clients. The recommendations touched on each of the five steps in individual rehabilitation: Selection of clients, needs assessment, choosing an intervention, monitoring / follow-up of clients during, and separation at the end of the rehabilitation process. The evaluators also suggested ways in which participation of clients in their own rehabilitation might be boosted, made recommendations for the organisational structure of programmes, on maximising community involvement and emphasised the importance of information systems and of investing in the programme staff. A number of recommendations were specific to the types of interventions implemented i.e. housing, education or micro-credit. Evidence for the impact of SER on quality of life of clients is limited but suggests increased self-esteem and increased respect and status in family and community.

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Hansen Disease Recoverers as Changing Agents

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The purpose of this study is to examine the activities of the patient associations and individuals to improve their living conditions and to reduce negative stigma and discrimination against Hansen Disease patients. This study can be done from the Sociological viewpoint using disability studies and social movement theories. The method is case study, one of the qualitative researches to reveal the ordinary life of people. I will focus Zen-Kan-Kyo, which is a patient association established in 1951, to unite the voice of those who are institutionalized in the National Leprosy Sanatoria. Data was collected from many sources, such as published matters, literatures, newsletters, and unpublished documents. Also, there were in-depth interviews conducted with the people who contributed to the association for a long time. As a result, it was recognized that patient associations challenged various fields and had a great influence on healthcare providers, politicians, mass media, and common citizens. In conclusion, it can be said that supporting patient associations financially, politically, and sympathetically is effective to improve conditions and reduce negative stigma. Key Words: Patients Association, Social Movements, Changing Agents, Case Study, stigma.

Stigma Against Leprosy Patients in Mahasarakham Province, Thailand

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Introduction: As stigma is a major treat to leprosy eradication, this study aiming to explain; the untoward behavior of health workers and people against leprosy patients, and the perception of patients. Method: Qualitative study using in-depth interviews and observations in 4 health workers, 31 people and 6 patients. Results: Majority of health workers had aversion to patients because of belief that leprosy easily spread, said that the people bad behaviors because of fear of leprosy especially severe symptom patients and thought that there was self stigma. Among people, females had higher proportion of fear than males. Elderly people had the highest proportion of fear because of inaccurate knowledge. A majority of patients with no disability did not feel discouraged but lost of self esteem, and were afraid of patients with bad image. Factors contributing to stigma among patients were; in accurate knowledge and belief. Most cause of fear is disease contracting. Conclusions: Stigma could result in disease spreading and emerging. All stakeholders, especially health workers should be the model by not expressing untoward behavior against leprosy patients. Leprosy knowledge should be transferred to new generation. Key Words: Stigma, Leprosy.

Community Participation in Empowering Development of Mae Lao Leprosarium, Chiangrai Province

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Introduction: The participatory action research on community participation in empowering development of Mae Lao leprosarium, aiming at social integration into normal community in the near future. Methodology: PAR, In-depth-interviews, FGDs, group process, AIC and community organization, Population involved in the study were 60 leprosy patients and 255 their family members, 55 leaders in Mae Lao leprosarium and two nearby communities selected for the study. Results: 76.64 percent of leprosarium members were satisfied with their present status and living, 65.69 percent expressed status-quo and 24 percent agreed to integrate the leprosarium into normal village. Findings from the study also revealed that two representatives from the leprosarium were already elected as members of tambol administrative authority to vote for financial support to community development of the leprosarium. Conclusion: Empowering development could enable leprosarium to be self-supporting on sustainable basis. In addition, attitude of nearby communities and related government and non-government sectors appeared to be positive and favorable for social integration. Key words: Community Participation, Empowering Development, Leprosarium.
Factors Contributing to the Poor Participation of Leprosy Affected Persons in SHGs

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The social inclusion for persons with disability into mainstream society is one of the important facets of any rehabilitation effort. The formation of integrated Self Help Groups is one of the strategies of bringing about social inclusion of persons living with the consequences of leprosy. However, in the Community Based Rehabilitation Program at the Schieffelin Institute of Health Research and Leprosy Center, we observed that the participation of persons affected by leprosy in the SHGs was poor when compared with persons with locomotor disabilities. The aim of this study was to identify the factors that contribute to non-participation of persons affected by leprosy in SHGs. We used both qualitative (Focus Group Discussion) and quantitative (questionnaire survey). A questionnaire was administered to 60 persons affected by leprosy who were members of SHGs and 60 who were not members of SHGs. For comparison, the same was administered to 60 persons with locomotor disability who are members of SHGs and 60 who are not members. Focus group discussions were held with the different groups in terms of gender and age group. The data is being analyzed and will be presented.

Overcoming Human Rights Violations Against People Challenged by Leprosy in Africa (Kenya) Within the Context of African Culture

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This paper will highlight the history of human rights violations against people challenged by leprosy within the context of African culture. It will explore how individuals challenged by this disease learned to adapt to the conditions that violated their human rights. It will also discuss the negative impact of these human rights violations such as secret burial sites, cultural ways of losing dignity and the negative belief systems that have developed against people challenged by leprosy. It will also explain new concepts, tools and strategies that IDEA Kenya has developed that are being used to solve this problem in the 21st century including Youth Empowerment Programmes and Ecotourism Programmes. Last but not least it will show some positive fruits of the new concepts being used to solve the problem of human right violations and illustrate how a bad history can be used in cultural tourism to empower the local community who have been challenged by leprosy and stigmatized by society. In conclusion, it will highlight challenges that are being faced as we work to solve the above problems and present recommendations on how to overcome human rights violations against people challenged by leprosy in the 21st century. Key Words: Human Rights, Stigma, Empowerment

Contribution of Leadership in Developmental Programme of Self Settled Colonies in State of Maharashtra

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Object: The main object of the study was to assess impact of the leadership towards the developmental programme of self-settled colonies & find out the programmes successfully implemented by the leaders. Preamble: In Maharashtra there are 37 self-settled leprosy colonies which were identified during the survey conducted by leaders in collaboration with IDEA India. Approximately 15,000 leprosy affected persons & around 30,000 family members living in the shadow of these colonies. During the survey it was observed that there is a good leadership coming up in the colonies which is involved in developmental programme of the colonies. So it was decided to major the impact of the leadership in the developmental programme of the colonies. Methodology: Questionnaire was prepared & data was collected through social workers working in the field of leprosy & having close contact with colonies. State level association namely Maharashtra Kushpitid Sanghatana has played an important role in this survey. Results: No. of Colonies Total families (No. of families) Total Popularity 37 15,000 45,000 Educational Status:- Illiterate 3209 Primary 4159 School 1726 Higher Secondary 222 Degree 68 Technical 18 Developmental work carried out successfully through leaders - 1. 100% Registration of the colonies with Government. 2. All the 37 colonies have got primary or secondary schools in their vicinity. 3. Leadership is responsible for creating awareness about the rehabilitation programme run by Government & NGO's among the colony members. 29 colonies out of 37 received assistance under Government scheme. 4. All eligible colony members have received Ration card & Voter's ID Card. 5. Leaders of different colonies organized the meeting with Chief Minister of state & Deputy Chief Minister of state. They have confidently interacting & putting their problems with Government authorities, Secretaries, Collectors at local level, which helps them to solve their problems. Conclusion: With the leadership colony has achieved good progress. It has helped in developing strong networking among the colonies. They started working under one banner which leads to unity of the people. So it is felt that leadership should be developed & trained at different levels.
Role of the State Leader

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Introduction: The role of A.P. State Leader aims at bringing all colonies under one Umbrella, to empower them in utilizing their rights, to increase their income, to get educational, rehabilitation, Medical, Health, and Monthly Pension facilities. Activities for Implementation: We met the Governor of A.P. and submitted our requisition to provide all facilities possible by the Government to the persons affected with Leprosy. It held Press Conferences in Hyderabad and also in other important Towns, to create awareness of our problems in the Public and Private Sectors. We conducted Interview with the beggars of the Leprosy affected, by the High Court Advocates at Vidyanagar Railway Station in Hyderabad. We sent our application to all the Ministers and all MLAs of A.P. State. We conducted a big Rally with 5000 Persons from Leprosy Colonies in Hyderabad. Achievements: The Government of A.P. responded and gave assurance to provide Anhyodaya Annayojana Ration Cards to the affected persons. The High Court Advocates, in participation with Human Rights Committee, filed a petition in the High Court demanding provisions to the affected persons. The High Court gave verdict to issue Bus-passes on concession to all the eligible affected persons. Hindrances: We find that the colony people want immediate result. They seem to have no patience to wait for result. They also do not help and Co-operate with the State Team particularly in respect of finance. With the help of some individuals, the team has overcome to some extent the financial Problem. Failure: All members in the Action Committee are very poor. So, they face monitory problem for their movement from one place to the other. Conclusion: However, we try our level best to convince the colony people by explaining the facts and get their support.

Economic Advancement

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Introduction: Generally, persons affected with leprosy live in poverty. Away from The Community due to stigma. Colonization: They do like to live with the persons like themselves. So, they start living in the colonies. Disability Act: A 1995 Leprosy cured persons are also included in the list of disabled persons under P.W.D. Act. Like provisions to certain categories like Backward classes S.C. S.T etc., they are also provided some facilities like monthly pension, free bus-passes, rehabilitation facilities, reservation in employment etc. Micro-Finance: Now a days, Micro Finance System helps people to increase income. We formed nearly 1500 Self Help Groups consisting of some leprosy persons in Khammam District of Andhra Pradesh. It is done in association with the Disability Association Net Work. They save some money and deposit the same in the bank. After half year or one year, the Government considers these S.H.Gs and advance loan for any income generating activity. With the help of this kind of financial help on nominal interest basis, the persons in these groups are able to increase their income and become advanced economically. GROUPS: In a Self Help Group consisting of 10 to 15 members. 1 or 5 persons belong to leprosy affected. Thus integrity of leprosy cured persons is also possible besides economic advancement.

Stigma and Discrimination

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Leprosy has been associated with stigma and social exclusion through out the history. Stigma can be defined as an attribute that is deeply derogatory. The stigmatized individual is one who is disqualified and rehabilitated from his social life, earning place, community religion, with no respect/ regard of his peers accorded, and putting him to shame, frustration and lack of self confidence that may generate suicidal tendency. Such suicide cases have been brought to my notice. Due to society’s stigma and unacceptance of leprosy suffers, they set up own colonies, own society and lead a new life practicing community religion freely. Concealment of early signs of leprosy results in more significant deformity. Rehabilitation of deformed patients, society’s acceptance of all leprosy patients have to be intensified. Incidentally, following movements/agitations carried out by us, about 500 ex-patients have been fully rehabilitated through Govt.- service, and their social acceptance also stands retrieved. The leprosy Mission, HKNS, GMLE and other NGOs have been found to be working in CBR. We are also doing similarly through Panchayet, Municipality, NGOs involvement by arranging poultry, goatery, piggery, etc. for the beneficiaries. In the integration process, stigma is difficult to be reduced fully. Even many doctors bear high level stigma against leprosy afflicted for which the victims, as indoor patients, do not get facilities that other general patients avail. Stigma can be bought by using non-discriminatory terminology, by repealing discriminatory lows and by making available accurate information about the diseases self – stigma can be reduced by support, encouragement and rehabilitation of the afflicted.

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Children Education-the Stair for the Improvement of Quality of Life

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Childhood is the most precious stage in a human. But education standard of leprosy sufferers’ children is pathetic and linked with socio-economic condition of the leprosy colonies. Out of 2156 children in W.B. State leprosy Colonies 1062 go to schools. Of 285 school non going children 80-100 accompany parents for begging. About 809 are under aged. Education has to be reached to this 1000 children, present resource is 5 Primary School and facilities for 225 students in the state leprosy colonies. Most children and parents posses no idea about higher education, bright future, and, hence their aversion to being educated. With education received boys and girls of 20 / 22 families have been able to bring about economic affluency in family while about 300 boys and girls with secondary level education received remain unemployed. Spread of colony education need as follows:-
1) Economic improvement of inmates 2) Colony with just 20 students need a primary School. 3) Free feeding, dresses, learning materials, special coaching arrangements is necessary. 4) Post education vocational training with assurance to became self reliant is required. 5) More free hostels, or expansion of seats of the existing hostels. 6) Family Planning in the colonies. 7) Political goodwill for spread of education in the colonies. Nowadays Govt. NGO, even Colony a person have organized themselves and is coming forward to over come the situation. Children also are gradually realizing the meaning of life-for living healthfully like others. Thus radical change of the colonies will encourage common people to integrate themselves with colony people.

Empowerment Workshops

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Introduction : In the modern times, people affected by Leprosy also are considered as citizens of India like any otherpersons.

History : In the past, due to Stigma and discrimination, they lived in colonies situated far away from residential areas.

Empowerment: persons affected with Leprosy are included in the list of disabled persons as Leprosy cured persons, with certain facilities. As they are innocent, there is a need to empower them with the knowledge of understanding their rights. 1st Work Shop : The First empowerment work shop conducted in Vijayawada in the beginning of 2006 with the help of IDIA-INDIA, was attended by the representatives of 56 colonies in the State. Out Come : Colony representatives understood their rights of enjoying primary needs of life, right to live, right to work etc., Ø They constituted themselves in to a Society at the State Level. The Action team elected by them visited all Leprosy Colonies in the State and imparted the knowledge to the colony people. Ø It conducted press meetings to create awareness in the Society and in the empowerment. Ø It started fighting to solve the problems of colony people for increase in pension, ration cards, bus passes, rehabilitation, medical and educational facilities, not only through request to the Government but also through filing a petition in the high court of justice. Ø The Government reacted to our effort and sanctioned AAY Cards. Bus passes, medical and rehabilitation facilities etc.

Integration of Leprosy Colonies with the Community

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Integration of leprosy colonies with the community Leprosy is an age-old disease. Due to social discrimination leprosy affected live as outcast in leprosy colonies. Leprosy creates problem that has different directions 1) Health, 2) Social, 3) Psychological, 4) Rehabilitation. Presently, MTD-treatment has almost arrested the disease. Now society’s outlook remains to be changed. For that, right information have to be reached to the society. a) Leprosy is curable, b) Leprosy is least infectious, c) Free treatment) Early detection/ treatment prevents deformity, e) Reconstructive surgery to correct deformity. It is time now that leprosy colonies be no more socially segregated. General community Be imbibed with ideas that they too are part and parcel of the society and that they form country’s human resources. In this regard society’s goodwill and scientific out look is essential. If necessary, we have to go to the community stressing that we are at no fault-we are but your man-and that is our great identity. Now the following arrangements have to be ensured in leprosy colonies for social integration. 1)Socio-economic Development,. 2) Education, Health Education,.3) Total treatment Provision,4) Games, cultural improvement, 5) Environment Development, 6) Patient Education,7)Marital Integration. By side by side, colony people owe responsibility of keeping their own surroundings beautiful. Because, man loves beauty. The first ward of the creation has been love. So, let us love each other and let this be the motto of our social and practical life. Thus, live and let live.

Gurupada Mandal Secretary.
Stigma and Un-Equality

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I whole heartedly welcome the learned delegates to the 17th International Leprosy Congress. I have chosen the stigma and un-equality of leprosy patients as my subject. Out of 350 persons affected by leprosy found during the survey by Sarathk Manav Kushthastram Ajmer Team, 100 persons affected by leprosy personal data was collected and the same was verified by the Coordinator Ajmer Sh. S.S. Rajput. The Extracts of the survey report is given below: Rajasthan was always a monarch state. In Ajmer during the Muslim rule the British Government entered in Ajmer politics through the English company medium. Because of the religious importance of Khaaja Sahab’s Tomb and the Holy lack of Pushkar there was an abundance of persons affected by leprosy visiting these places in the hope of curing themselves. According to the survey the ratio of persons affected by leprosy is 3% Hindus and 21% Muslims and the local persons affected by leprosy were 76%. Considering leprosy as stigma the ration of Muslims community was 13% and Hindu community was Nil and the stigma ratio was 10% in males and 3% in females. The feelings of the society and friends as leprosy being a stigma towards the family and persons affected by leprosy as in the ratio as 82% normal behaviour and 15% males and 3% females were treated as people to be avoided. The result of all this behaviour was that 13% persons affected by leprosy were treated as stigma and hence they had to depart from their homes for the benefit and marriage in their family. One more truth also came forward that even after leaving their family these persons affected by leprosy use to help their family monitorily. The data also show that persons having deformity had to face the above said troubles, where as persons affected by leprosy without deformity were treated normally. So we can conclude from the above matter that as 82% persons affected by leprosy were treated normally and leprosy was not treated as a stigma. As far as un-equality of persons affected by leprosy is concerned the ratio is 26% Muslims and 3% Hindus. The scenario of un-equality in mode of transport was reported to be 3% and in government hospitals 14% persons affected by leprosy were treated as people to be avoided and the stigma in the working places of persons affected by leprosy was 12% with no difference in male and female persons affected by leprosy. From the above we can come to the conclusion that persons affected by leprosy who were deformed had to face the un-equality stigma while traveling. The second most important fact which has come to light is that in government hospitals all persons affected by leprosy if they are monetarily poor or even if their behaviour is beggary they are ignored by the medical staff. On the basis of the result of the above survey we can say that even though the persons affected by leprosy are deprived from their families and society they still have a desire to live. There is not even a single evidence of any persons affected by leprosy committing suicide and the biggest surprise is that even though these persons affected by leprosy are deprived of being a part of the family still praise and pray for the benefit of their family. Lastly I would request the learned members to note this point that treated persons affected by leprosy are not concerned about their reputation but are eager about their family self-reliance and health. There should be a guarantee that persons affected by leprosy should be made healthy then only we can look forward in making them useful members of the society. Once persons affected by leprosy are healthy they will themselves work like normal human being of the society and the stigma of leprosy will vanish. I would also like to add alongwith the above that if deformed persons affected by leprosy can be cured medically of their deformity this will be a miles stone in their struggling life. Thanking you, Jai Hind.

The Influence of the Change of the Terminology Leprosy by Hanseniasis in Former Patients Residents of Former Hospital Colony

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The use of the terminology leprosy and yours derived it is prohibited in Brazil by the law promulgated in 1995. (Law nº 9010 of 29/03/1995). This legislation was defended by some specialist doctors, mainly Dr Abraão Rotberg and by the Movement for the Reintegration of People Afflicted by Hansen’s Disease (MORHAN). This work evaluates the influence of this terminology change in the former-patients’ life that suffered the social isolation and still stay as residents in former-hospitals colony. The methodology used was the oral history through semi-structured individual interviews, audio-recorded, after signature of consent term. Upon analysis of the interviews it was inferred that the substitution of the terminology leprosy by hanseniasis just contributed to minimize the stigma and for most of the interviewees, what really made difference in the social life was the proposal of a really effective therapeutics that made unnecessary the compulsory isolation. These results can supply subsidies for the elaboration of proposals in the sense of rescuing the residents’ citizenship in former-colonies for leprosy patients and inclusion in a fairer social context. Leprosy, hanseniasis, leproserie in Rio de Janeiro state.
The Sociological Study on the Formation of the Foreign Aid Project’s Models of Korean Hansen People’s Organizations

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Introduction: Early 1990’s Hansen people in S.Korea also made organization to help Hansen people in many countries who still have experienced discrimination, segregation and hunger. It is significant that the Hansen people who the receiver of the aids now help the groups sharing similar experiences. In this paper I will focus on the formation of the foreign aid project’s models of Korean Hansen people’s organizations. Methodology: 1. Analyzing several government documents, medical news papers, anniversary books of Hansen people’s foreign aid organizations. 2. Interview with the leaders of Hansen organizations, Hansen people in Korea and Philippines, workers of WHO. Result: 1. There are several socio-structural elements affecting the establishment of these organizations. Firstly, the Korean civil society expanded their range of activities into oversea, in this case especially Korean Hansen people started to work and to meet foreign Hansen People and encountered their miserable lives sympathizing with them in overseas. Secondly, they share the experiences of economic development and religious activities. 2. The Korean international aiding works are divided into the social development-orientated model and the mission work-orientated model. Two models, however, are not clearly distinguished from each other. They are in consistent negotiation and conflicts. 3. The Korean Hansen oversea aid works are changing according to the inner and outer situations of Korean Hansen society. First of all, they started to work not only for Hansen people but also for other people in needs. Moreover, the working area is also expanding in two models. Conclusion: The work models of the Korean Hansen oversea aiding agencies developed in ‘path dependency’. The oversea aiding works are determined based on the Korean Hansen people’s experiences rather than on the needs of local Hansen people. Therefore, the merits and demerits of Korean Hansen experiences can be succeed into the oversea Hansen works.

Magnitude of Educational Problem in the Colonies & an Attempt to Overcome It

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Object: To collect detail information on educational background of the children of Leprosy Affected Persons & their problems. Preamble: It is understood that the students living in the colonies do require some support. To understand the Magnitude of their problem a study was conducted in collaboration with IDEA India & Hind Kushnt Nirvan Sangh in selected colonies. Methodology: Personal interviews of students & parents from the colonies were conducted; also base line data was collected through questionnaire. 726 primary students, 122 higher secondary students were interviewed along with their parents in this Pilot study. Problems identified: 1. Majority of the students were from socio-economically backward sections hence financial support is require to complete the higher education. This is the basic need. 2. Some desirable students find it difficult to get the admission for higher education due to competition. 3. Fee structure for various professional courses are also very high which leads to no admission in the respective institution to get admission. 4. Due to their Leprosy background some students requires psychological support to regain confidence. Suggestion: 1. It is observed that financial support should be provided at primary & secondary level to maintain the continuity in education. 2. Eligible students of higher education should be given assistance in fees. 3. Personality development programme should be organized for all students to build the confidence. 4. Competitive exams training programme should be organized. Continuous financial, psychological support counseling helps the student to complete their studies. Some beneficiaries of such support has obtain degrees in Engineering, B.Com, M.Com, etc.
Role of State Leader in Development Activities

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In the battle of leprosy, leadership’s role is under deniable. For leadership a scientific organization is necessary. For solution of the problem leadership should know its different aspects, its depth, existing mechanism for solution and practical sense. He should posses fighting spirit ability to train honest, trust worthy and fighter companion through organization’s branch/district level sittings meetings and issue based movements. In 1978 during our initial movement period, leprosy sufferers lived out cast in shops, ponds, conveyance, offices, temples, etc. Struggling against the hindrances through sustained agitation, in the field of education care of old aged, employment, removal of stigma its success is partly achieved. But yet the issues like Dressing out fit with expt. Dressers in colonies and sub centres, MCR shoe supply, all treatment facilities in leprosy Hospitals, high level Research an anesthesia, infertility etc., State and Central level rehabilitation budget, pension, Patta, are to be met. Early treatment, proper subsistence for the afflicted, deformity prevention, publicity of elementary science of leprosy constitute firm base of social rehabilitation .With deep motherly feeling Mother Teresa draw leprosy victims near her heart while many NGOs are devoted to leprosy work in our state. Joint programmes on health education with HKNS & MKNS we have performed. Presently ILU has taken initiative NGOs net working. State leader should know details of Govt. and NGO activities, In this respect we have quite some drawbacks yet. Until realization of total emancipation from stigma, complete rehabilitation, organization and state leaders work would go on.

Experience of Self Empowerment

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The author describes in his paper the success he met in marketing his products. One is the computer software he developed for accounts maintainance, the other about the marketing of agarbathis made by village ladies who were below poverty line and the third one is about manufacturing, packing and selling of dhoop sticks made by handicapped leprosy patients who formed as association for themselves. About 10 persons were motivated in to this project. As a person affected by leprosy the author describes as to how he openly admitted to the prospective buyer about his health and how the society received him with out any stigma. Also he narrates his experience with voluntary organizations like Rotary clubs and Lions club and their offer of help towards the cause of handicapped. Summarizing the paper the author claims that any resourceful person affected by leprosy should project himself as a role model and snatch the initiative. He claims that stigma in the minds of patients should be eradicated first and then only they can meet the challenges of the society.

An Educational Video Construction – Life Doesn’t Stop:
Recognizing and Curing Leprosy

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Leprosy is an epidemiologic relevance’s disease in Rio de Janeiro which shows high detection levels and late diagnosis. The necessity to make educational activities in leprosy more intense, motivated the Rio de Janeiro’s Municipal Secretariat (SMS/RJ) to produce a film named: “Life doesn’t stop: Recognizing and curing leprosy”. The goal was the disease’s disclosure among the health units and the people in general. This study describes the making off the video elaborate in Rio de Janeiro city in 2003. The main questions come from researches around leprosy’s socials representations with sick people, their families and health area professionals. A multidisciplinary team worked on the film making, having as partners SMS/RJ and FIOCRUZ. The project was guided by clinical experiences, health area professional researches, and meetings with patients. The study result is a 13 minutes video, where patients’ speeches are mixed with scientific information. The sicken, fears and doubts, signs and symptoms, treatment and cure are described by interviewed people. A new conception of an old disease is the best lesson taken from words and smiles of those who lived leprosy. In addition it shows the solidarity of those who talk about their lives. Keywords : Educational video, New Conception, Leprosy.
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Stigma: The World's Laws of Silence

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Stigma is an act of labeling, rejection, or unexplained fear of a person. Stigma has historically been very difficult to measure in a scientific manner primarily because of vast differences in language, geography, nuances, and culture where these actions have been conceived and blossomed. Therefore, the purpose of this presentation will be to show how, by the dearth of objection against the practice of labeling and rejection, these acts have become acceptable actions. Many laws have been enacted throughout the world which mandated the incarceration and/or isolation of persons diagnosed with, and/or suspected of having, leprosy. Also, unwritten laws—unspoken expectations—have contributed to the existence of stigma. Finally, the sarcastic and inappropriate use of offensive terminology frequently will solidify the pyramid of stigma. However, it has been the attitudes and blatant behaviors of many to focus their attention in opposite directions when rejection and labeling have been practiced. Consequently, stigma has continued, giving legitimacy to the laws of silence. Conversely, the common puzzle of humanity has the potential to assist in abolishing the laws of silence.

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The “Persistent” Challenges of Leprosy Colony Hospitals in Brazil

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Introduction: The lack of an effective therapy for leprosy treatment led the Brazilian government to adopt the policy of compulsory isolation in the beginning of the 20th century, by constructing colony hospitals in all states of the country. This abandonment and the government’s disregard concerning the maintenance of those institutions, as well as the compulsory isolation policy, gave rise to serious social problems, which includes family dissolution, patients suffering from stigma, and the losing of their citizen’s rights. The purpose: of this paper is to demonstrate that many of the problems identified inside those colony hospitals, due to the adoption of such a policy, persist to the present time. The methodology: comprises a bibliographical review and an evaluation of updated reports of those institutions. The results: show that the colony hospitals continue to present serious structural, human, and social problems, in spite of some progresses that were identified in the last two decades.

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Leprosy in Children – Follow up Study

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The child rate in leprosy new cases still remain about 7 to 15 percent. It means that in previously described as endemic area and with current detection of about 1000 cases there are 70 to 150 children being detected every year. With a view to understand what happens to these unfortunate children once they are diagnosed and treated, Novartis CLC Association started the Leprosy Children Care Program – aptly described as “Looking After Future”. The following statistics have encouraged us to continue this as regular activity. Total number of 87 children were examined. Ten cases (11.5 %) had thick nerves and were classified as high risk. Four (5 %) already had developed deformity. Sixteen cases (18.4 %) were having multiple patches or MB leprosy. Twenty eight cases (32 %) had definite patch and were in the category of cured patch. What was more interesting was that twenty nine cases (33 %, almost on third cases) had no sign of leprosy, meaning thereby either the patches had disappeared or something was amiss in the diagnosis. It is necessary to go in the detail of both high risk cases and the cases which had no evidence of leprosy. The social out look was represented by the fact that almost 97.7 % of these were attending the school. Not withstanding the fact that education is free, school bags were gifted to all and those in need of support for education will be identified. The human interest story in respect of one case is exemplified by the fact that on the demise of the mother, father remarried and the daughter (leprosy case) was adopted by mother’s sister. She was being cared for as if she is her own daughter. NCLCA plans to facilitate her studying further.
Mainstreaming of Leprosy Colonies

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Introduction: The introduction of MDT has resulted into a drastic decline in both PR & NCDR with reduction in visible deformities which is the root cause of stigma. But the assembly of old and deformed cases in the colonies sustain the stigmatized social outlook and the citizens are living a poverty-stricken isolated lives compromising with human dignity. Rehabilitative measures for their mainstreaming are utmost necessary as revealed in a study conducted in 38 colonies in West Bengal and Jharkhand. Objective: To reveal the need, significance and impact of mainstreaming of the colonies and to develop appropriate rehabilitation measures to contribute to the national development process. Method: An extensive survey was conducted in 38 colonies to assess the living conditions, Socio-economic status, social outlook, educational & Training status, livelihood, social barrier, social participation and finally need of the inhabitants to bring them into social mainstream. Result: Five basic components for mainstreaming were found to be necessary: 1. Old-age-care-Home for old, Blind & disabled persons. 2. Vocational Training, Placement, Micro-credit & Sales networking for the productive age group. 3. Educational Assistance to students from colonies. 4. Reconstruction & renovation of houses with basic amenities. 5. Practical access to the general Health Care system. Conclusion: Social outlook & stigma continue till the Leprosy colonies will continue. Human dignity, economic self-reliance, productive life and education are the basic factors for empowerment which need to be ensured. Multi-sectoral involvement of the Development Agencies and the Government for effective social mainstreaming is required to meet the needs of the colony dwellers and thus to develop them as contributing.

Social Status of Leprosy Affected Persons – A Legal and Human Rights Perspective

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Every leprosy patient has equal right for access to prompt diagnosis and treatment for leprosy. In India, this is facilitated with the integration of leprosy diagnosis and MDT services available at all public health centres on par with other diseases. Although remarkable achievements are made in the epidemiological and medical spheres of leprosy elimination, the legal, economic or social discrimination and isolation resulting from physical illness or handicap due to leprosy has not received due concern. The Govt. of India also had passed a ‘Persons With Disability Act – 1995’, granting special concessions for the ‘leprosy cured’ persons including job reservations. In practical terms, this Act does not benefit the leprosy-affected persons. In 2005, the UN Human Rights Sub-Commission has passed a resolution by expressing lack of legislative or administrative measures and appealed to end such discrimination and stigma affecting the leprosy victims. This paper will present the existing discriminatory legal provisions that are against the interest of leprosy-affected persons. Possible measures to promote the dignity and equal rights of the leprosy-affected persons are discussed. We strongly recommend that any intervention aimed to rehabilitate the leprosy-affected persons should be integrated with the general rehabilitation services. Persons disabled due to leprosy should be treated on par with other disabled for social support.

Assessment of Stigma Among People Affected by Leprosy in Khartoum, Sudan

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Stigma affects the effective control of the leprosy. By understanding stigma effective measures can be designed to tackle it. A study was conducted in Khartoum, Sudan to assess the degree of perceived stigma and associated factors among people affected by leprosy. The Participation Scale was used to measure participation restriction in patients on treatment and those after completing treatment. Respondents were systematically recruited from two clinics in Khartoum for a period of two weeks. People affected by leprosy known to be living in two community areas were randomly selected into the study. The interviews were conducted in Arabic by trained interviewers and consent was obtained from all respondents interviewed. The study interviewed 68 respondents, of whom 33 were on treatment and 35 from the community after treatment. With a cut-off of 12 on the P Scale, the study found that 77.1% of respondents after treatment have participation restrictions, as compared to 15% who are still on treatment. Those restricted have similar characteristics such as visible deformities, low level of education and unemployment. Respondents on treatment show higher restriction among those with MB leprosy. It is concluded that perceived stigma of leprosy is higher among people affected living in the community with visible deformities. POD will reduce stigma. Key words: Stigma, Disability

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**Impact of Socio-Economic Rehabilitation on Leprosy Stigma in Northern Nigeria : Findings of a Retrospective Study**

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This study explored the perceptions of people affected by leprosy regarding impact of socio-economic rehabilitation (SER) on stigma reduction. The study combined a quantitative questionnaire (the P-scale) with semi structured interviews of 20 individual SER participants, five focus group discussions and 10 key informant interviews. The P-scale results showed that four men suffered significant participation restriction (scores >12 points) in finding work and in social integration. The narratives of SER participants, focus groups and key informants showed that SER improved self-esteem, financial independence, acquisition of new skills, and access to public institutions. The authors speculate that through the pathway of improvements in economic and living conditions, SER is beginning to influence the process of social interaction, resulting in positive attitudinal change towards SER participants. The subjective opinions of interviewees suggest that improved self-esteem, positive family and community support for SER participants and increasing participation in community activities are indications of stigma reduction.

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**Social Mobilization -"A New Weapon for an Old War"**

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Many strategies have been adopted worldwide aiming at controlling leprosy, which nevertheless still remains a serious public health problem in some countries. As an aggravating factor, reports and prejudiced attitudes from individuals of different segments of society persist. This fact may be related to the focus of qualifications, which are only aimed at the health professionals. Discomfort with this situation led to the search for an alternative approach, to the involvement of other partners in control actions. The methodology is all about mobilizing the population, especially agents who play leading roles, as a strategy for an effective social inclusion of the leprosy patient or former patient. It is believed that the population, when mobilized, will disseminate information, thus building a new social representation for the disease in addition to actively participating in the targeting of policies and actions which promote this process of inclusion. The information will also contribute to the discovery of hidden prevalence, enabling, in this way, a rupture in the chain of transmission and the reduction of late diagnosis. The methodology adapted itself to different audiences, and reaffirmed the importance of Social Mobilization. **Keywords:** leprosy, social mobilization, community leaders.

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**In Search of Healing Springs : The Historic Bond Between Hawaii and Japan**

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There has historically been a strong bond between people whose lives have been challenged by leprosy in Hawaii and Japan. In the late 1800s and early 1900s this centered around the search for a cure, that led people to the Kusatsu Hot Springs. People traveled long distances to bathe in these healing springs. Treatment often included being punctured with 300 heated needles before bathing. It was painful, expensive and often discouraging. In the 1880s, the Gojo Bath treatment was introduced to Hawaii and for more than 20 years remained the treatment of choice for the people of Kalaupapa. In 2007, family members of Kalaupapa residents joined residents of Kuriyu Rakusen-en Sanatorium to visit the grave of Kaoru Shukuzawa from Hawaii who had made the long journey to Kusatsu in 1914, dying there in 1926. The modern-day bond between Hawaii and Japan centers around a deep and vital understanding that no treatment, no cure, is complete unless it is accompanied by a restoration of the family ties that were severed in the days when there was no cure. **Key Words:** Human rights, discrimination Stigma, Social Aspects, Restoration of Family Ties.
CLEAR-IDEA Rotary Programme: Experience of Self Empowerment

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It is a unique Project by Rotary Dist.3200 Established in 1999 for Physical and socio-Economic Rehabilitation of leprosy affected person and their children. This Project could be implemented by Rotary Clubs worldwide to help Leprosy affected person and their children. By this Project we have been able to transform lives of leprosy affected person and elevate them from below poverty status. The first aim was to educate their children and prevent dropouts due to lack of finance and also to prevent child labor. 1. Educational Scheme: Many of their children’s lives have been transformed and they have become software Engineers, Doctors, Nurses, Paramedical workers and Vocational training in Electrical and Mechanical. I. Socio Economic Rehabilitation a) Micro Credit: By giving Micro Credit without interest rate, we are able to prevent them from falling into the clutches of money lenders with exorbitant interest rates. b) Sanitation and Hygiene: By providing Bore wells, Hand pumps, Bathroom and Toilets, their life conditions have improved. c) Low cost House: Low Cost Houses have been provided in collaboration with Govt. schemes. II. Physical Rehabilitation: a) Reconstructive surgery, Intra ocular lens (IOL) implementations have done for affected person.

Increased Voluntary Reporting of Leprosy Cases with Special IEC Campaign After Integration – GLRA/ Swiss Emmaus India

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Introduction: Leprosy is associated with stigma and erroneous beliefs in the minds of people. IEC can bring lasting changes in the beliefs and attitudes of the people. After integration awareness building was given top priority to promote self reporting of leprosy cases. The national statistics show that currently more than 150,000 new leprosy patients are registered annually in India. German Leprosy and TB Relief Association & Swiss Emmaus, two International Organisations working in India for more than 50 years, carried out extensive IEC campaigns on Leprosy in selected pockets of 26 districts, especially the geographically difficult terrains in collaboration with the respective District Health (Leprosy) authorities. Methodology: Three remote PHC’s were selected in each district covering on an average of 1 lakh population in 4 days time. Detailed orientation on leprosy and IEC method was given to all participants and empowered them on better communication skills. Each worker visited around 100 houses / 300 persons every day and educated them on leprosy through Inter Personal Communication (IPC). Distributions of pamphlets on leprosy, public mike announcing, displaying banners were few other tools used. A total of 96 staff including 3 Medical Officers, 8 supervisors and 85 volunteers (General Health staff, ICDS workers, Nursing students and local NGOs) involved in each campaign. Results: During the campaign 527,885 houses were visited and 2,578,270 people were educated on Leprosy. 2997 suspect persons were referred to the nearest Health Centres for diagnosis and management. Among them 752 new leprosy cases were registered including 117 children. After analysis it was noted that the new case detection had gone up five fold compared to pre campaign case reporting. This trend was similar in all districts. Conclusion: By IEC Voluntary Reporting of new suspects increased. The campaign facilitated training of General Health Staff. More number of special IEC programmes should be encouraged in remote & difficult to reach areas to enhance self reporting of new leprosy cases.

Concerns Affecting Younger Women in Eversley

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Life of younger women affected by Hansen’s disease can be truly harsh, impacting us socially, physically, mentally and spiritually. It involves painful separation from family and friends; it gives many younger women sleepless nights. It somehow created so many questions in our minds—why things happened this way; why we got this disease; what have we done wrong. We understand that there are medical programs for people affected with the disease; we understand the efforts of social workers, health workers and other professionals, but still the socio-psychological aspects of Hansen’s disease brought into our lives, is dreadful at times. While younger and still new to Eversley and taking MDT, we were taught how to take care of ourselves; we have participated in youth leadership training, in addition to learning in school. Four younger women have received scholarships to attend school. In spite of the stigma, we are still hopeful that a brighter future awaits us if we, the younger women, accept that there are things that we cannot change, but we being young can do something to make a difference. Key Word: Stigma.
Discriminatory Law Against People with Leprosy: Barrier Towards Integration of People with Leprosy into Society

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All discriminatory laws introduced during the medieval period are still in force. These laws were introduced to prevent common people from transmission of disease. During the Rana regime two leprosariums were established in Nepal—one in Khokana close to Kathmandu and another in Malung about three hundred kilometers west of Kathmandu. People affected by leprosy were forced to stay in the sanctuary and not allowed to leave the institution. The discriminatory law permits one to seek divorce from one's spouse on the grounds that his spouse has leprosy. If the wife has leprosy, the degree of discrimination is doubled. She is forbidden to seek support for her life from her husband. This disease was placed into the category of dreadful and highly contagious diseases by law. Interaction with persons affected by leprosy in public places was forbidden. Today this serves as the basic reason behind discrimination against people with leprosy. This status has prevented affected people from integrating into their community. Key Words: Human rights, discrimination.

Retrospective Cohort Study on Social Status and Family Acceptance Before MDT, at RFT and After RFT

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Leprosy is a biosocial disease. Effective Management requires not only cure and prevention of physical disabilities, but a concern and action to prevent social problems. Being a stigmatized disease, it is necessary to monitor the changes in social status and family discriminations while on MDT. A study was done at 102 leprosy patients who completed the prescribed course of MDT at our referral hospital, comparing their status before MDT with the situation at the time of release from treatment (RFT), and assessing their current status. Family acceptance changed from 92% before MDT to 86% at RFT, and further declined to 73% at present. Community acceptance also declined from 95% to 88% to 77%. Self-esteem seems to have increased and the patients' social withdrawal increased from 19% to 28% to 34%. Desire to live and accomplish something remained the same. The patient's body image showed significant improvement. These changes are studied by age, gender, type of leprosy and disability status. Health services must take more responsibilities to care for the leprosy patients holistically, and ensure that rehabilitation and loss of self-esteem does not occur. Key words: family acceptance, social status, leprosy.

Empowerment Through Education of Children

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Children are the promise of humanity for tomorrow. Education plays a pivotal role in the growth and development of any society and nation. The persons affected by leprosy were thrown out and used to settle down by themselves and families in exclusive colonies. The children of leprosy patients as well as those affected by the disease needed financial support to pursue their education. Due to the difficulties in finding resources they used to drop out from places of education. To overcome the above scenario IDEA India had launched an educational support programme and supported over 1300 children hailing from 58 patients' colonies in the state. Many children who had completed their education were placed in good jobs after training. Various educational support rendered through IDEA India have been helping to empower the families of those helped to improve their living conditions and to re-establish themselves like any other. Providing education to the future generation is a genuine need and desire of human society. It is natural for a human being to want to be a human being and fight for his right to exist with dignity. The children of leprosy patients and those affected by leprosy are no exception in this regard.
Impact of Housing in Leprosy Stigma Reduction

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In order to assess the impact of low cost housing to the leprosy patients on reducing the impact of stigma against leprosy, a survey was conducted on 30 beneficiaries, who were assisted in building permanent houses under the Low Cost Housing project of The Leprosy Mission and the results were presented here. Data were collected by interview through structured questionnaire. All the beneficiaries of 'Low Cost Housing' project are visibly deformed, and live in rural community. The average family size is five. 92% of the beneficiaries are living in new houses for more than two years. Before permanent houses were built, all were living in thatched houses and 65% of them expressed that they were ignored by local community, not invited/accepted in social gatherings in the neighborhood and similarly, the community members avoided visiting these families. Only 19% of those who had stigmatized experience said that they themselves had a feeling self-stigma and did not invite others into their homes. After started living in newly built better houses, 96% of the beneficiaries experienced that there has been change in the attitude of the community, which was evident as the family members are being invited for social functions by the community members. **Key words**: housing, stigma reduction.

A Study on the Prevalence of Stigma Related to Leprosy, HIV/AIDS and TB Among School Students in India and the Effectiveness of the Methodology to Reduce Stigma

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**Introduction**: The goal of the study is to gauge the extent of prevalence of stigma about Leprosy, HIV/AIDS and TB all being stigmatized diseases on a much larger scale than the originally believed. Based on the analysis of the study it was proposed to reduce the stigma against these diseases through intervention stigma reduction programs, thereby paving the way for acceptance of disadvantaged persons and communities enabling equal opportunities for them in society. **Methods**: A multi centric, cross sectional, representative study was carried out through questionnaires. Students in the age groups 12 yrs to 17 yrs both boys and girls from Government and Private schools studying in the 7th to 12th standards from 30 districts comprising 14 states of India in both rural and urban centres. **Results**: With regard to individual diseases, 89.6% of those surveyed registered an overall increase in knowledge about leprosy with 8.1% registering a very significant increase. The figures stand at 89.4% for HIV/AIDS and 91.0% for TB. 84.7% surveyed had reduction in perceptions of stigma related to these diseases. **Conclusions**: The positive results showed that the program has been hugely successful in increasing awareness levels and in reducing levels of stigma.

Self Help Groups of the Persons with Disability - An Agent of Change

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**Need for the study**: Any developmental activity should bring in some change. This project strives to bring change in the lives of people with disability in terms of Socio-Economic status, quality of life of the members of the Self Help Group. **Conclusion**: The members of the Self Help group get more social acceptance than before. They have gained self esteem. They have savings in their bank which gives them some security. They have more access to the bank than the able bodied. They are aware of their rights and the Government benefits and how to access them. However the members lack vision which needs to be developed. **Key words**: self help groups, self help in disability.
**Micro - Credit as an Effective System to Improve the Quality of Life of Leprosy Affected and Other Disabled People in South India**

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**Introduction**: Due to disabilities and reigning beliefs, most of the leprosy affected and other disabled people are unemployed and have a very low standard of living. Only about 2% of the disabled people in India receive the aid to which they are entitled. The Micro credit system has been tried to improve the ability of the disabled individual to achieve social security and decrease their vulnerability.  

**Methods**: Development activities were carried out in 2 rural and 2 urban districts. Financial group work through micro credit was employed and both economic improvement and social acceptability were assessed. **Results**: 76.75% participants reported increased financial capacity and 88.84% achieved greater social acceptance. Other benefits included improved awareness, upliftment of the status of women and better control over decisions that affect their lives. There was reduced dependence on money lenders and non institutional sources.  

**Conclusions**: Holistic, sustainable and integrated development of human life and social acceptence was achieved through this system by better attention to the special needs of the disabled.  

**Key words**: Micro credit system, disability, social sciences.

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**Needs and Quality Care Issues of Women with Leprosy**

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**Introduction**: Given the gender inequalities, leprosy affected women are likely to report late and default more during MDT. In order to determine to what extent women leprosy patients needs and expectations are fulfilled a study was done at a Leprosy referral hospital in Kolkata. **Methods**: All women leprosy outpatients (104) were interviewed and physically examined. **Results**: 46(44%) were below 40 years of age, 17 (16.3%) were unmarried, and 13(12.5%) were separated/divorced. 30% were illiterate. 63% belonged to poor socioeconomic status. 44% came alone, 30% were brought by father/husband. About 93% had leprosy related problems. Nearly 60% already had visible disability. For 90% of patients, this was a visit for recurrence of complications. Almost all patients expected medical treatment as well as self-care skills. 25% were still ignorant of the early signs, causation and spread of the disease. Nearly 60% preferred to hide their disease. The need for repeated visits to the hospital was very difficult in terms of cost, time away from responsibilities at home.  

**Conclusion**: Effective treatment though available, is often not accessible, especially by women, partly due to distance, transportation cost, domestic responsibilities and not having the power to make health decisions them selves. An aspect of quality care often neglected in practice, is lack of privacy for women during history taking and examination, toilets and separate waiting areas.  

**Key words**: quality of care, women with leprosy.

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**A Study on Community Based Approaches for Reducing Leprosy Stigma : Community’s Perception**

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Reduction of stigma against leprosy has traditionally been attempted through IEC methods along with leprosy control work. As an attempt to develop innovative strategies of leprosy stigma reduction by community action, a survey was conducted with one of the main objectives to assess people's suggestions and preparedness towards community based stigma reduction programmes is one of the main. Nearly 2,400 community member (heads of households) and 600 leprosy patients were interviewed. Further, 60 key informants were interviewed in depth and 100 focus group discussion were held in the three states viz. West Bengal, Uttar Pradesh and Chattisgarh. The results suggested some interventions such as organizing village level meeting in which leprosy patients also participate, Health camps in the village where leprosy patients as well as other are treated together and the villagers could observe the normal behavior of doctor with the patient, Cultural programs through folk song and folk dances like chhou, baul, jhumur for leprosy awareness, Common feast be organized during any local fare where patients will serve food and Public garden maintained by the leprosy patients etc. Generally, there was a favorable attitude towards reducing leprosy stigma and communities are enthusiastic to take initiative in the above programmes.  

**Key words**: community based approaches, reduction of stigma, community and stigma.

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Integrated Community Development Program, Delhi, India - A Five Year Journey

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Since 2001 The Leprosy Mission evolved a practical community-based integrated development module leading from an institutional model to a community-based model and finally to a programme entitled "from Margin to Mainstream". Nearly 46,168 persons with physical and social disabilities have been helped through counseling, provision of assistive devices and development of skill as well as placement in economic activities. During 2006-2007 the programme has taken a more concrete shape involved actively several communities including slum population in Delhi. A major initiative was taken towards capacity building which included training on community development, exposure to community development activities and establishing of linkages through awareness generation. Details of inputs, processes, outputs and outcomes are presented with discussion on future lines of action. It is concluded that specific capacity building and involvement of critical groups in the community such as youth and women contribute significantly to the transition from margin to mainstream and from dependency to freedom. Key words: integrated development, development in leprosy.

Formation of Village Committees for Reduction of Leprosy Stigma: A Community's Approach

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Non involvement of community is probably the significant reason for little change in leprosy stigma even after decades of leprosy control work. A survey was conducted in the three states of West Bengal, Uttar Pradesh and Chhattisgarh, with the specific objective of assessing community's perception towards community-based action towards leprosy stigma reduction. Data collected from all the three states emphasized formation of village committees in each village. Interaction of trained social workers placed as Community Organizer to facilitate the community-based action, as per their perspective, lead them in forming a Stigma Reduction Organizing Committees (SROC) in each village. Thus a total of 60 SROCs were formed from three states. Experiences of forming SROC in different states suggest that a successful working committee must have their native leader/sarpanch as chairman and consists of 12-20 members with representation from females and various castes, formally meeting twice a month in the presence of chairman. Most of the SROCs, as per their plan, organized health/skin camp in their own villages to establish better rapport with the community and some of the SROC members visited TLM hospital to get educated about leprosy to enable themselves organize community-based action programmes for leprosy stigma reduction. Key words: village committee, stigma reduction in leprosy, village participation in stigma reduction.
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IEC - a Methodology in Leprosy Elimination
Tamilnadu Experience

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Tamilnadu, a southern state of India has a population of 661.67 lacs (March 2007) with an area of 1,30,058 sq.km. It is one of the front-runners in Health indicator and infrastructure in the country. Leprosy has always been a disease of high prevalence in Tamilnadu (118/10,000-May 1983). It gave birth to the SET/LCU Programme in 1955 as the State National Leprosy Control Programme. Dapsone mono therapy was introduced in Tamilnadu in 1940’s, when the prevalence of Leprosy was very high. Multi Drug Therapy (MDT) was introduced in phases in all the districts of the State between-1983 and May 1991 when the State had a prevalence of 118. Elimination was achieved at the State level in March 2005 and at the District level March 2006. It is working towards the block level elimination by 2012. General Survey, School Survey and Contact Survey were the main tools for detection and diagnosis of Leprosy in the community. Awareness was generated by the Health Education through the Leprosy Health providers. With the integration of the Programme in State into the State Public Health System in July 1997 the vertical programme was disbanded into the District Programmes. A pan-state IEC Programme was conducted by the State Govt. Health Department, DANLEP, N.G.O’s and peoples participation to increase the awareness of Leprosy. This has resulted in an increase in the Voluntary Reporting of Cases. The figures are given below:

<table>
<thead>
<tr>
<th>District &amp; Block PR Range of Tamil Nadu as on Mar 2005-2007</th>
<th>No : of Revenue Districts – 30</th>
<th>No : of Blocks – 385</th>
<th>PR Range as on 31-03-2005:</th>
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<td>Block</td>
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</table>

The District wise figure indicating the Voluntary Reporting rise will be presented in the paper. Key words : Prevalence, elimination, integration, awareness.

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High Degree of Social Restrictions in a Former Leprosy Colony, Ceara State, Brazil

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Throughout history, leprosy patients have been suffering not only from physical disabilities, but also from social exclusion. This study aims to measure the social restriction perceived by ex-leprosy patients residing in a former leprosy colony in Redenyao Municipality, Ceara State (North-East Brazil). We used Van Brakel’s Participation Scale, an interview-based instrument assessing client-perceived social participation on a score system (0-90 points). It is used in leprosy patients, but has so far not been applied in a former leprosy colony. We obtained data from 77 (85.6%) of the 90 leprosy-affected residents of the colony who have been successfully treated. In total, 52% showed social restrictions, indicated by a score > 12 points. Restrictions were mainly related to working and travelling and less common in activities in the closer community. Social participation was significantly lower in individuals with mobility restrictions (p<0.001), and visible deformations (p=0.01). The perceived restriction of social participation is an important consequence of leprosy among the population of a former leprosy colony in North-East Brazil.