

This helps reduction of work load on the field workers and admission in hospitals and also brings down financial burden on the Government as well as other institutions working for leprosy.

For the training of leprosy effected persons/family members/community volunteers, a simple kit is devised by me for use of leprosy effected persons. While I was working as District Leprosy Officer, Chittoor, I have tried the kit on 170 disabled patients in G.L.C. Unit, Puttur which has yielded very good results.

Hence I feel, if this type of kit is supplied and training is imparted to field workers, who in turn will train leprosy effected persons/their family members/Community/Volunteers, it will go a long way in prevention and management of deformities in leprosy.

This process will help the leprosy effected persons to prevent and manage the deformities and live with dignity, and self-reliance.

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Di 418

PLAN FOR RECONSTRUCTIVE SURGERY AMONG DISABILITY PATIENTS OF VISAKHAPATNAM DISTRICT

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The study is undertaken to analyse the leprosy patients requiring re-constructive surgery among the disability patients of Visakhapatnam, coastal district of Andhra Pradesh. There are 2821 patients with disability. It is recorded that the patients grouped for re-constructive surgery is analysed by limb wise, fitness wise and will- ingness wise.

Patients with hand disability (claw fingers) are 937, out of which 248 (25.4%) patients are fit for surgery and the remaining 725 patients (74.6%) are not fit for surgery for various reasons. Patients with foot disability (foot drop) are 329, out of which 117 (35.5%) patients are fit for surgery and the remaining 212 patients (64.5%) are not fit for surgery. Patients with eye disability are 84, of which 16 (19%) are fit for surgery and the remaining patients 68 (81%) are not fit for surgery.

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Di 419

EXPERIENCE OF THE DISABILITY PREVENTION PROGRAMME IN VISAKHAPATNAM DISTRICT

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The data of the disability patients of Visakhapatnam, coastal district of Andhra Pradesh is collected and analysed taking up various parameters like age, sex, organ-wise and grade-wise involvement. There are 2,864 disability patients in 37,272 total living patients in the district giving 7.68% of disability rate in the district.

Men are 1990 (69.5%) and women are 874 (30.5%). Adults are 2843 (99.3%) and children constitute 21 (0.7%). Grade I are 716 (25%) and Grade II are 2148 (75%). Hand involvement alone is 508 (17.7%), foot alone is 872 (30.5%), eye alone is 25 (0.9%). Two limb involvement (hand, foot and eye) is 106 (3.7%).

Individual deformities are worked out and the care services are planned as per the need.

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Re 50

SOCIAL REHABILITATION OF ADDICTED H.D. CASES THROUGH INSTITUTIONAL AA GROUPS IN LEPROSY INSTITUTIONS

K. Ganapathy, A. Beine & Sr. Roslin T, SN, Sivananda Rehabilitation Home, Hyderabad

Six years ago, the first institutional AA-group (self-helping group of Alcoholics Anonymous) was started at Sivananda (Leprosy) Rehabilitation Home, Hyderabad, India.

The decision to support forming such an AA-group among our H.D. cases, suffering as well from Alcoholism, was made after seeing 2-3 rehabilitated H.D. cases dying at relatively young age due to Alcoholism - related diseases.

Forming institutional AA-groups in leprosy institutions was found much easier to achieve than fostering or initiating an AA-group in the society among the general poor sections of the population.

Hence this social aspect of rehabilitation of the poor among H.D. cases is highlighted and support to form such institutional AA-groups is highly recommended for leprosy institutions. It is also found that this type of social work is helpful for POD (prevention of deformities), that it makes addicted H.D. cases earlier fit for reconstructive surgery and it further helps to improve

regularity of attendance in out-door-clinics of leprosy control centres.

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Re 175

ILEP GUIDELINES FOR SER OF PEOPLE AFFECTED BY LEPROSY - THEIR APPLICATION AND RESULTS IN FIVE LEPROSY PROJECTS OF LEPRO INDIA

V.Prabhakara Rao, P.V.Ranganadha Rao, D.Rajesh, Tilak S.Chauhan & D.D.Palande Secunderabad

The impact of MDT during last two decades has helped in a better understanding of the scope and perspectives of rehabilitation in leprosy.

LEPRO India has started rehabilitation programme since 1997 in 5 of its ongoing leprosy projects. The programme is holistic in nature with a multi disciplinary approach to address the concerns of treatment, POD and POWD. The approach has recognised the importance of assessing the impact of leprosy on the individual and the need for the programme to be responsive to the concerns of the individual, family and community. The spectrum of activities consists of need assessment involving the client, family and community, counselling and educational interventions to address self stigmatisation and stigma, formation of village rehabilitation committees and self help groups as partners in rehabilitation process, training of beneficiaries needing skills, liaison with other agencies for providing assistance and follow up to assess the improvement in the quality of life of beneficiaries and sustainability of the interventions.

ILEP guidelines have been formulated in 1999 for organizing rehabilitation services in leprosy. A retrospective analysis of the SER activities implemented in LEPRO India projects indicates that the programme was largely structured and implemented in conformity with these guidelines. The SER strategy in these projects, the activities taken up, the results, impact assessment to identify changes in the socio economic levels of the beneficiaries and the relevance of the guidelines in further strengthening the SER programme are discussed.

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Re 261

A STUDY ON SOCIAL ASPECTS OF LEPROSY REHABILITATION

Wang Baoren, Bijie Prefectural Institute Of Dermatology, Guizhou, China

Among leprosy patients in Bijie prefecture of Guizhou province, 76.16% developed various kinds of disabilities: mixed disability in 34.83%, psychological and social disability in 14.7%, and physical disability in 16.62%, indicating the magnitude of patients with leprosy in need of rehabilitation, work load and manpower. As for the needs of rehabilitation, economic and comprehensive rehabilitation formed a considerable proportion, accounting for 34.1% and

50.06% respectively. Physical and psychological rehabilitation form a base of leprosy rehabilitation, the final goal of rehabilitation for disabled must be comprehensive rehabilitation. The outcome from the implementation of rehabilitation projects demonstrated that physical and psychological rehabilitation projects had the advantages of less input, quick positive response and good acceptability by leprosy sufferers, and were easy to popularize. Implementation of economic rehabilitation project depended on the patients physical condition, their living environment and local market situation. Even though a relatively large amount of input was needed, the outcome was quite good. Without support from society at home and abroad, comprehensive rehabilitation project was difficult to be carried out.

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Re 292

EXPERIENCES OF AGRICULTURAL TRAINING IN REHABILITATION OF PEOPLE WITH DISABILITIES IN NEPAL

Karen Baxter, Pokhara, Nepal

Introduction

Situation of People With Disabilities (PWD) in Nepal

Approximately 90% of the people in the Western Region of Nepal work in subsistence agriculture. It is estimated that 10% of the population have disabilities including people affected by leprosy.

Our aim here on the Rural Development Farm (RDF) on the Green Pastures site is to assist families and communities to enable people to help themselves and fulfill their role as participating members of society and not only to assist the PWDs.

Working in agriculture can often further increase peoples disabilities, so training is in the prevention of disability field as well as in technical training.

Method

Assessment of PWD s needs by RDF and social

worker staff.

Developing a training curriculum in consultation with OT dept. of Green Pastures Referral Hospital and others [eg, Drug Rehabilitation & Aids Prevention (DRAP)]

Training, with much practical involvement on the part of the trainee, has been modified to continually improve the service and is now for up to a month, is farm and community based, & can include business training too.

Follow-up is done regularly by social workers and RDF staff to individuals, families and groups to continue to assist and improve physical and financial welfare.

Continued on next page Results - self confidence

- forming own self help group, - financial stability
- improved status in community- independence or interdependence - changed attitude/behavior

Discussion: Are we achieving our aims ?

How can we improve the assistance we are already giving ?

Can we join with others in the same area to give and receive our experiences to further enhance our services?

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Establishment and development of Self-help-groups : Self-help-groups are known to be a useful tool when developing any scheme for PWD. These groups may need assistance whilst forming. For example, sensitization and understanding about the needs of PWD, vocational and business training and technology transfer.

Development of micro-finance schemes :

Schemes must then be developed that meet the economic and social objectives whilst also being suitable for the Self-help-groups.

Rationale for credit (loan eligibility criteria) must be developed along with interest rates, and methods of loan processing and monitoring that are appropriate for PWD. Monitoring should allow for indicators to develop such that the scheme evolves with time and experience. Handover of the scheme (to the Self-help-group) must be planned from the start.

Continued on next page Conclusion

Achievements : Have the social and economic objectives been met? Are the scheme and project sustainable? What are the second generation spin-offs?

Longer Term : How can the project be expanded to bring benefits beyond PWD? How can PWD be mainstreamed into Nepali society?

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Re 298

THE DEVELOPMENT OF AN APPROPRIATE MICRO-FINANCE SCHEME FOR PEOPLE WITH DISABILITIES IN NEPAL

James Chinnery & Mukti Sharma, Pokhara, Nepal

Introduction: Situation of people with disabilities in Nepal : Nepal is amongst the worlds lowest income earners. Approximately 90% of Nepalese are subsistence farmers. It is estimated that 10% of the people in the Western Region of Nepal have disabilities. People with disabilities (PWD) may be employed in lower paid and more dangerous jobs, they may be exposed to insecurity or violence at home and in their communities and they are generally less educated with fewer opportunities to learn. PWD will also face many barriers to obtaining credit. Disability tends to lead to poverty and poverty leads to further disability.

Micro-finance alternatives : Various micro-finance schemes exist, such as Revolving Loan Funds and Guarantee-cum-risk Funds. Which are most appropriate for PWD in Nepal?

Method: Formation of goals : Goals must be developed which are specifically related to needs of PWD.

Re 302

EXPERIENCES OF MICRO BUSINESS SKILLS TRAINING OF PEOPLE WITH DISABILITIES IN NEPAL

Megan Grueber & Shrijan Gyanwali, International Nepal Fellowship, Pokhara, Nepal

Partnership For Rehabilitation (PFR) facilitates suitable income earning opportunities for people with leprosy, and other disabilities. People require vocational skills to enable income earning opportunities, and business skills to sell their product or skill. PFR develops our clients basic business skills by offering formal training on a Micro Business Skills Training Course.

The target group includes any client who has received vocational training and business support from PFR. It is designed to be participatory, practical, and result oriented. We have found this training course to be effective for a number of our clients. Evaluation tools include a training evaluation questionnaire completed by the participants, a business evaluation form that is completed by the social worker during a follow up visit to each client, and general discussion with client and other business owners in the area.

Having used these evaluation tools, the training course has been modified to include more practical exercises rather than lecture style presentation. It has been identified that for some people an extra short course on a specific subject, such as account keeping or marketing, will be beneficial to build on their base knowledge of running a business. Another important part of the training reinforced through evaluation is the necessity of on-site (at the persons business place) follow-up and evaluation.

In conclusion, having evaluated four Micro Business Skills Training Courses, this method of skill training appears to be effective for this target group. In future we recommend that this course includes practical exercises, on-site evaluation and follow-up. Short subject specific courses can be investigated to complement the basic course. Clearly the development of this course is an ongoing process to enable the target group to successfully participate in income generating opportunities.

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Re 303

SOCIO-ECONOMIC REHABILITATION IN MID-WESTERN REGION OF NEPAL

Lalit Gurung, International Nepal Fellowship, Kathmandu, Nepal

The rehabilitation programme is part of the tuberculosis leprosy project to help the people affected by leprosy with severe disabilities or deformity and handicap in the mid-western Nepal, especially for those with the suffering due to adverse physical, social and economic consequences of their disease.

People affected by leprosy with disability have to face the negative attitudes from the society, even it will have the difficulties for the whole family too, because they need to care for the disabled people with financial, emotional and social support. This support will become a big burden for the family, the disabled people also have less opportunity to get a job or marry in the normal social life as others.

The main aim of the rehabilitation programme is to integrate the clients back to the community and rebuild their own self esteem. For the physical rehabilitation, the programme is very concerned about the prevention of impairment and disability activities in their daily lives, our key workers will train the clients about the prevention management and do the follow-up time to time with the family and the community. The whole programme is offering different assistance for the clients in business creation, integrated education, vocational training and job replacement, living support and housing.

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Re 362

ISSUES IN THE REHABILITATION OF PEOPLE AFFECTED BY LEPROSY - A CASE STUDY FROM NEPAL

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For centuries, people in many societies have become socially isolated due to the physical, psychological or social consequences of leprosy. Widespread evidence has shown that the segregation of people affected by leprosy reinforces leprosy stigma and creates negative images of the disease. This has contributed to the increasing provision of rehabilitation facilities to enable rehabilitated people to return to mainstream society. Recently the policy of Community Based Rehabilitation has successfully resulted in fewer people affected by leprosy becoming socially isolated in the first place. It is also generally accepted that institutional facilities are needed to care for those who are severely disabled and have no external support, particularly the elderly. However, there seems to be little acknowledgement or provision for people who choose to opt out of mainstream society, usually because of their experience of severe leprosy stigma. This study from Nepal examines a range of coping strategies adopted by people affected by leprosy faced by debilitation, whether from choice or necessity. A spectrum is proposed which relates the coping strategy to the degree of social integration. This puts forward an individual's perspective on the issue of social isolation/integration although this is not necessarily the view shared by the leprosy agencies or the World Health Organisation. The study finds that whilst the latter ideally aspire to full social integration of all people affected by leprosy, the goal of a small proportion of individuals may be to remain isolated.

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Re 403

CHANGE IN SOCIAL AND ECONOMIC ASPECTS OF BENEFICIARIES IN COMMUNITY BASED REHABILITATION PROGRAMME

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Objectives: To find out the changes in social economical and living conditions, pre and post community based rehabilitation programme.

Design: Descriptive retrospective study. All the beneficiaries in community based rehabilitation programme from 1991 to 1999 are included in the study.

Settings: Community based rehabilitation leprosy patients from urban and rural areas of Leprosy Control Unit of Philadelphia Leprosy Hospital, Salur of A.P. State.

Participants: All the beneficiaries of community based rehabilitation programme of Leprosy Control Unit, Salur.

Main Indicators and outcome measures

Different percentages have been taken into consideration.

Results: The percentage of different categories is high like expansion of unit, change of living conditions and getting income by community based rehabilitation unit. Also the percentage of beneficiaries who are actually benefitted with community based rehabilitation programme is high. The percentage of male beneficiaries improvement in different categories is little higher than female beneficiaries.

Continued on next page 76% beneficiaries expanded their units. Improvement in amenities is 34%, but at the same time, economical improvement and change of living condition is 72%. Beneficiaries getting income through community based rehabilitation are of 81%.

Conclusion: There is an improvement of beneficiaries in economical status. Though the percentage of improvement in acquiring amenities is low, the programme of community based rehabilitation has helped the beneficiaries in improving their economical and living condition. So the programme of community based rehabilitation helping leprosy patients to live on their own without depending on anybody. It gives them satisfaction to live happily.

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Re 405

HANDA'S ACTIVITIES - A CONCEPT OF HOLISTIC REHABILITATION

Chen Zhiqiang, Yang Lihe & Ruth C. Winslow, Guangzhou, China

Leprosy has been a disease not only affecting people on the physical part, but also causing social, economic and psychological problems. Though not many active cases now exist in China, there are about 250,000 people affected by leprosy alive still facing a great difficulty of living due to the stigma and discrimination. HANDA (IDEA CHINA), Hansen-Damien Rehabilitation & Welfare Association dedicates to working together with the community for the social, economic, physical and psychology rehabilitation of the people affected by HD. The following activities have been carrying out in 4 provinces in China.

Advocacy :

Bringing dignity and respect to the individual by being an advocate and voice to the government for the people, publishing and distributing materials about the disease and the people, especially that written by the people and representing of the people in international forums where they can share their views with medical professionals.

Social-Economic Rehabilitation:

Micro economic empowerment projects is to enable the people to be greater self-supporting and self-confidence, which include fruit trees planting, livestock raising and traditional quilt making, etc.

Skills Training Programs:

HANDA organizes and conducts skills training seminars and workshops to empower people with a skill and self-confidence and enable them to find work either in a factory or live independently. Sewing school, leadership empowerment workshop and basic finance management training are some example.

Continued on next page Physical Rehabilitation:

HANDA is striving to meet physical needs and improve the quality of life for the aging and severe impairment population through: Foot Care Project, Eye Project and upgrading the living conditions of leprosy villages.

Education Scholarship:

Support children of HD affected persons who do not have access to education as a result of inadequate income or community rejection. Now 198 children from six provinces are under the umbrella of the scholarship.

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Re 408

REHABILITATION OF LEPROSY PATIENTS

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Christian Fellowship Community Health Centre, Ambilikkai, Tamilnadu, has its Leprosy Rehabilitation Centre established about quarter of a century ago, way back 1968. Taking care of the ulcers of anaesthetic feet and hands are the most common problems, we have to face in our project area. Of course, poor socio economic status is another obstacle in our way of rehabilitation. The vast majority of the patients are farmers or daily labourers, so care of the cured patients feet and hands are important. Even though we supply a pair of micro cellular rubber chapels to all such patients free or partially free and educate them how to prevent the ulcers of their extremities, they frequently visit our hospital with such problems. Bed rest, good food and clean dressing of ulcers are enough for their rapid healing. The well-to-do literate leprosy patients are also subjected to foot ulcers; their number is much less and recurrence is rare. Now-a-days, the number of patients coming for reconstructive surgery are few for various reasons. All correctable deformities and willing patients are already corrected by surgery. Our main rehabilitation is employment of the ex-patients. We have employed 46 cured leprosy patients in our various institutions like hospital, lathe and welding workshop, agriculture, shoemaking, and in dairy farm, etc. some of them are watchmen, security staff and ward aides.

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So 79

GENDER ISSUES IN THE SERVICE DELIVERY TO LEPROSY PATIENTS

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In the context of the recent increased awareness of gender issues, this study was taken up to discover what, if any, were the gender issues in the service delivery to leprosy patients, so that suitable solutions could be worked out.

Hospital and Leprosy Control Unit records of The Leprosy Mission, Calcutta, for 1999 were examined and gender wise statistics for Hospital attendance, new case registration at hospital, and the leprosy control unit, and hospital admissions were noted. 100 patients, 50 male and 50 female, taken randomly from OPD were interviewed and asked questions regarding the time lag before seeking treatment and the reasons for delay if any.

The total number of patients receiving MDT at the hospital was 477, of these 364 (76%) were males, and 113 (24%) females. Likewise taking the total hospital attendance figure of 6672, of which 5424 were males and 1248 females, only 19% were women. The number of women attending the hospital was 23% of the number of men attending the hospital. Significantly,

the new case registration at the leprosy control unit, where the patients are detected and started on treatment at home, showed the following figures - 404 males and 240 females, which are much closer to the expected ratio, of the number of female patients being approximately half the number of male patients. The number of women being admitted for complications of leprosy was also much lower than expected. The average delay in seeking treatment was much greater in the case of females than males. 57% of male patients consulted a doctor before 6 months while only 27% females patients did so. The reasons females gave for the delay in seeking medical help and for not being admitted when necessary were also noted.

This as a preliminary report giving us some tangible figures showing that women leprosy patients do have a more difficult time obtaining and continuing with their treatment than men have. So if we are to aim for elimination of leprosy worldwide we will have to think carefully and find some solutions for these women.

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KAP STUDY IN A TRIBAL LEPROSY PROJECT FOR EVALUATION OF IMPACT OF IEC INTERVENTIONS

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LEPRA India is running a leprosy project in the tribal districts of Koraput and Malkanagiri in Orissa for the last 8 years. The project covers 1.5 million population in 6096 villages located in very difficult terrain. The tribal people speak 8 tribal dialects.

MDT is implemented since inception of the project and 14000 cases were recorded and treated. IEC activities were implemented by different approaches. A specially equipped IEC van was utilized to screen films and conduct public meetings.

A KAP study was conducted in the project to assess the impact of IEC interventions. A questionnaire was administered to 280 persons, comprising of teachers, leaders and community members selected by random sampling. The responses were analysed.

The findings and the areas needing special emphasis for IEC interventions have been summarized.

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