Community-Based Rehabilitation (CBR) & Leprosy International Workshop Report

Bangkok, Prince Palace Hotel (Thailand)

21-22 February 2009

The International Workshop on Community-based Rehabilitation (CBR) & Leprosy was organized jointly by Disability & Rehabilitation team of World Health Organisation (WHO) & International Federation of Anti-Leprosy Associations (ILEP) in collaboration with Ministry of Health, Government of Thailand, Global Leprosy Programme of World Health Organisation and International Association for Integration, Dignity and Economic Advancement (IDEA).

Technical Coordination of the International CBR & Leprosy Workshop was by Dr. Hugh Cross, Dr. Wim van Brakel and Dr Sunil Deepak, from the ILEP Technical Commission (ITC) and by Mr. Douglas Soutar, General Secretary of ILEP.

Organisation and logistics of the International CBR & Leprosy Workshop was by Italian Association Amici di Raoul Follereau (AIFO), Bologna, Italy.

Report of the International CBR & Leprosy workshop is prepared by Dr. Sunil Deepak, Head of Medical Support Department, AIFO/Italy. The pictures are curtsey the presentations made by participants during the workshop.

Report on International Workshop on Community-based Rehabilitation (CBR) & Leprosy

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EXECUTIVE SUMMARY

The International Workshop on Community-Based Rehabilitation & Leprosy was organised in Bangkok (Thailand) from 21 to 22 February 2009, on the occasion of the First Asia Pacific Congress on Community-Based Rehabilitation (CBR).

86 participants from 20 countries participated in this Workshop (Annex 1 provides a list of participants).

The Workshop was organized in three thematic sessions: Experiences on the evidence base for CBR and leprosy, twin track-approaches to ensure equal opportunities for persons affected with leprosy and the application of WHO CBR Guidelines for development of rehabilitation services for persons with leprosy related disabilities. There was a final summarising session. (Annex 2 provides the Workshop Programme).

Experiences on the evidence base for CBR and leprosy: The first session included presentations on basic principles of CBR and their significance for leprosy related work, measuring impact of micro-credits, transformation of leprosy-specific self-care groups into multi-disability self-help groups and assessment of disabilities.

The presentations were followed by group discussions on the following themes: ensuring quality of care, promoting empowerment, indicators for impact assessment, changing work attitudes of health professionals, conflict resolution and challenges in developing self-help groups.

Twin track-approaches to ensure equal opportunities for persons affected with leprosy: The second session included presentations on challenges of integrating leprosy affected persons in general disability programmes, main-micro credits for persons with leprosy related disabilities, additional factors of vulnerabilities affecting integration and experiences from Timor Leste, Congo and Bangladesh in twin-track approaches of inclusion and integration.

The presentations were followed by group discussions on the following themes: cooperation between ILEP & disability organisations, role of organisations of persons affected with leprosy, leprosy specific self-help groups or cross-disability self help groups, approaches in areas where no CBR services exist, integration of services for persons with similar disability needs and integration of CBR in general development.

Application of WHO CBR Guidelines for development of rehabilitation services for persons with leprosy related disabilities: The third session included presentations on implications of CBR guidelines for leprosy programmes, successes and challenges in adopting CBR approach for leprosy programmes, CBR programme and leprosy services in Thailand and role of organisations of persons affected with leprosy in promoting human rights approach.

The presentations were followed by group discussions on the following themes: challenges of integration and inclusion, rights based approaches and persons affected with leprosy, participation and inclusion of leprosy affected persons in CBR programmes, self-stigma and process of empowerment, measuring impact of socio-economic rehabilitation, and, leprosy and human rights.

Final Session and conclusions: The final session started with a presentation on principles and priorities for action. This was followed by identification and tasks through the "Nominal Group" technique. The following priority areas for reflection and action were identified:

- Inclusion and opportunity to participate: Understanding the processes, challenges, preparation & training needs and implications of promoting inclusion of persons affected with leprosy in general CBR programmes and enlarging the scope of leprosy specific rehabilitation services to persons with other disabilities.

- Finance and resource allocation: The twin-track approach of integration and inclusion between CBR and leprosy, as well as adopting the different areas of CBR matrix require preparation, capacity building and adequate resources.

- Collaboration-coordination: There is need for greater collaboration and coordination in the field in the countries where different ILEP member organisations are working, to learn from each other and to support each other.

- Facilitation: The term can be understood in different ways, how CBR approach learning can be facilitated, how persons and programmes facing challenges can find advice, how the group together can continue a learning process.

- Networking: There is need to network with other disability and development organisations at national, regional and international levels so that mainstreaming of needs of persons affected with leprosy occurs and at the same time, organisations and programmes working in leprosy can learn and strengthen their work.

- Rights based approach: After the approval of the United Nations Conventions on Rights of persons with disabilities and the leprosy related initiatives of UN Commission on Human Rights, there is greater awareness of the Rights-based approach but there is not enough understanding about translating this approach into practical daily work of leprosy services.

- Evidence: While there are growing numbers of experiences of inclusion and integration between leprosy and CBR in different countries of the world, there is not enough work on collecting evidence about different approaches and strategies used in the field and their advantages and limits.

- Appropriate terminology: Persons affected with leprosy and their organisations are asking the organisations and professionals to review the leprosy related terminology used in the field.

- CBR-CBD links: The issue of links between community-based rehabilitation (CBR) and community-based development (CBD) is much wider and needs to be seen in context of different disabilities including its implications, needs, processes, etc. for rehabilitation needs of persons affected with leprosy.

Conclusions

While there are many challenges facing the integration-inclusion of CBR approach & programmes on one hand, and on the other hand, specific rehabilitation centres and services related to persons with disabilities due to leprosy, still the workshop was important in the sense that it did not limit itself merely to identification of challenges and making recommendations. A large number of positive examples of how this "inclusion-integration transformation" is taking place in programmes supported by ILEP member organisations were presented, that can guide future developments and that need to be shared more among ILEP members.

Availability of tools that can help, including the WHO and ILEP joint publication on CBR and the forthcoming WHO CBR Guidelines, is another important support in promoting this transformation.

Still, only a limited amount of information was available about the significance and impact of CBR-leprosy interface. Though some scientific review of this work has been done, it is not yet shared with others and much more can be done in this direction and ILEP ITC can an important role in this area.

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Workshop Report

Opening Session:

Mr. Douglas Soutar, General Secretary of ILEP moderated the inaugural session, introduced and asked Dr Mahotarn to open.

Dr Krisada Mahotarn thanked WHO and ILEP for holding this workshop in Bangkok. In December 2008, he visited leprosy project that National Leprosy Programme had supported since 1956. They have also been supporting leprosy research from national funds. National Leprosy programme started in 1957 and started MDT in 1984, leprosy prevalence was officially reduced to less than 1 per 10,000 population in 1994.

There are about 80,000 leprosy affected persons, 5000 persons treated for leprosy related disabilities and there are 12 old leprosy colonies in Thailand. Promoting social integration and CBR approach is used with support from local authorities and other stakeholders. He expressed hope that the workshop will give them ideas on how to promote CBR management for persons affected by leprosy and to encourage communities, health services and welfare organisations. He welcomed all participants.

Dr Myo Htoon from Global Leprosy Programme, thanked all participants on behalf of World Health Organization (WHO/GLP), explaining the need to develop new activities and strategies for rehabilitation of persons with leprosy. WHO/GLP is now developing Global Strategy for next five years and output from this workshop will be useful to this new strategy.

Mr. Douglas Soutar introduced ILEP, a federation of 14 anti-leprosy associations. He felt that the challenge today is how we can think outside of constraints of leprosy and how CBR approaches can help us for mainstreamed inclusive communities. ILEP has a Technical Commission (ITC) with eight experts to provide guidance for members and one of the tasks they have is to guidance on how to improve coverage and quality of CBR. It is a workshop, so everyone is expected to contribute with ideas and experiences actively. It is important to identify the future tasks. He mentioned the recent CBR and Leprosy guidelines published jointly by WHO/DAR and ILEP.

Mr. Chapal Khasnabis from Disability and Rehabilitation team of the World Health Organisation (WHO/DAR) explained the logic of organisation of different workshops linked to first Asia-Pacific CBR congress. He explained that leprosy sector is very close to his heart, he has worked in the field and comes from disability background. Today's challenge is inclusion and there is still need of medical care. A great job has been done and challenges for future go more towards human rights, social inclusion. So far there has not been so much integration between disability work and leprosy and it will be advantageous for both. The new Global Leprosy Strategy is a good opportunity to contribute in this direction. WHO/DAR is also working with ILEP and need to work together more closely. Even in disability sector, leprosy is isolated and no one cares about survivors of leprosy and this situation has to change. In disability movement there is north-south divide, and the sometimes, outcomes do not help the developing world, but if voices from leprosy affected persons are raised, this may benefit all society. In WHO CBR guidelines, there are 3 specific chapters – on leprosy, HIV and mental illness. This is a twin track approach, promoting specific work on leprosy and at the same time, promoting mainstreaming. WHO CBR Guidelines should be ready by December 2009 and it will be another instrument for

all partners to work together. WHO through its call for "PHC – Now more than ever", is promoting all the heath related work in the same spirit.

SESSION 1 THE EVIDENCE BASE FOR CBR IN RELATION TO LEPROSY EXPERIENCE, session coordinator *Hugh Cross*

Backbone principles of CBR Guidelines, Johan Velema: The basic principles of inclusion, empowerment and sustainability are key factors that constitute the backbone of CBR Guidelines. These touch on all the different facets of life and they benefit all the persons. The presentation analysed different aspects of inclusion, empowerment and sustainability, including considerations related to persons affected with leprosy.

Measuring impact of micro-credit schemes and income, Isaac Gnanapragasam: Different German and Indian organisations from different sectors came together to develop a tool to evaluate the impact of savings and credits. This tool helps grassroots organisations to steer their activities towards positive impact. It is simple and participatory, can be used by illiterate persons. It starts from people's knowledge and it helps in making social changes more visible. It looks at intended and unintended, positive and negative, short or long term, and sustainable or temporary, impacts of activities. It looks at different changes, important incidents and interventions. These include participatory wealth ranking (PWR) for selecting candidates for intervention; Situational analysis and goal establishment (SAGE); performance assessment of the group (PAG); and performance assessment of NGOs (PANgo). www.ngo-ideas.net is the website which gives more information about joining this network.

They did a one year study with more than 200 Self-Help Groups (SHGs); they found an improvement from baseline of 32% to now of 70% on different indicators related to participation, empowerment in different domains. Their experience is that if SHG are composed of only leprosy affected persons, they take longer to work and develop.

Development of leprosy Self-Care Groups (SCGs) to multi-disability SCGs, Ramesh Choudhary: They did a Knowledge, Attitudes and Practices (KAP) survey and found that leprosy affected persons feel that stigma is related to the presence of infected foot ulcers. They have a self-care training centre. They provide 2 weeks home-based environment training at this centre. They identify the "at risk" leprosy affected persons. So far, they have promoted 41 SCGs including many non leprosy affected persons. Project aims to eliminate stigma, & promote empowerment. Their aim is that SHGs should become self-governing, self-funding NGOs. SCGs have also started spontaneously and they are helped and supported by existing SCGs. Other persons with disabilities, they do not receive specific self-care advice, but they participate in more general training like rights, management, etc. The SCGs are doing their own advocacy now. They have developed strong & positive identity and they provide development opportunities to other persons in the villages.

Assessment of disability in Nepal, Madhusudan Subedi: The situation of disability is not known, the districts are covered very little, and thus there is a big gap between what is reported and what happens on the ground. There are areas of overlap between organisations, in some areas there are many organisations and in other areas, there is no one. Since the resources are limited, it is important to understand better the real situation and to use the activities judiciously. In this initiative, they also collect narrative and case stories of persons.

Group presentations and discussions

Group 1, How to ensure quality of care/rehabilitation in a multitude of Self-Care Groups and Self-Help Groups (SCGs/SHGs) and monitor their progress: The discussions were presented by Jayanth Kumar. During discussions, the group developed 7 indicators to monitor quality and progress of SCGs/SHGs. These indicators are – coverage of needs of all the group members; level of satisfaction of group members; ability of the group to self-function; new initiatives by the groups themselves for example, from self care going towards self employment; the openness or the accessibility of the group to accept other persons; the networking with other groups; and, success or the ability to mobilize local resources.

Group 2, Methods and tools for empowering persons with disabilities: Group discussions were presented by Ranganadha Rao. In the group there were 5 persons from Government organisations, 5 were from NGOs and 2 community level persons. Group looked more at methods, as it was felt that tools can be developed locally. The important methods were: listening; right information; involving persons in decision making from the first stage; improving awareness and human rights; giving authority; developing skills; meeting peer leaders and sharing experiences; savings and micro-credit activities; creating relationships and trust among the groups.

About the development of SHGs, the group felt that these – can be only leprosy affected persons, or can be mixed groups. For promoting empowerment, they should also look at the following issues – public advocacy; scope for employment; gender attention; removing physical, social and other barriers; networking and mainstreaming with other agencies; drama, cultural activities, etc.; create legal body to fight for rights; and, look at issues of supporting immediate needs.

Group 3, "What indicators to use for outcome/impact assessment": Group discussions were presented by Carin Rensen. The group used the different domains of the CBR matrix and the basic principles of CBR Guidelines (inclusion, empowerment and sustainability) and then added goals to each and finally tried to look at indicators for each. More time was spent on these preliminary areas and they could only look at health domain. For example, while discussing "health and empowerment", the goal was choice of health seeking behaviour and indicator can be percentage of persons who have this choice.

Group 4, What methods can be used to assist health workers to encourage to transfer the locus of control from health professionals to disabled people: Group discussions were presented by Andrew Harding: The group felt that for such a change, we need to look at a number of areas such as – training of professionals; non-threatening language; attitude; hiring the right staff; involvement of disabled persons or leprosy affected persons as health workers; environment friendliness such as not having white coats; move away from biomedical to broader view like ICF; using role plays to understand different positions; in service training; "I can do" method promoting in staff; working in groups; exchange programmes and networking with other groups; mixed groups mixing strong and weak persons; work in both directions for empowerment; a policy commitment and management of the change – should have support of higher management; people know their roles and can be flexible; to model facilitation – health staff needs time to talk and listen to people.

There was also a discussion about the word "patients" in the group and it was felt that words like "ex-patients" should not be used and our discussions were broader for different groups of persons with disabilities.

Group 5, What are the most appropriate ways to resolve conflicts and to promote cooperation amongst SHG members?: Group discussions were facilitated by Michael Chen. There were 11 members in the group, from different countries including India, China, Thailand, etc. and it had both male and female members. The group came up with 10 suggestions that were prioritized – identify common interests among the group; group members feel ownership about the group; conflicts may be due to unequal information sharing so better communication and information management strategy should be there; there should be participatory decision making; group needs clear goals and objectives; common understanding about functioning of group with clear guidelines is needed; when conflicts happen, sometimes an outside facilitator is needed, at the same time group also needs some clear mechanisms for resolving conflicts; leadership in the group is important for resolving conflict; limit to an optimum size to about 15 to 20 persons as members of a group.

There can also be conflicts between the groups, like between groups of leprosy affected persons and other disabled persons. They may need to network with other marginalised groups to become stronger. Common interests and policy for conflict resolution were two most important priorities.

Group 6, What are the main threats to the success or development of SCGs/SHGs: The Group was facilitated by Mani Mozhi Natrajan and presentation of group discussions was by Isaac Gnanapragasam. Persons may be scattered in a village and meeting may be difficult so it may be better to have more localised groups, if needed in collaboration with other disabled persons; heterogeneity or homogeneity of groups can be facilitator or impediment and creating a federation of the groups may help; sometimes, due to stigma, persons may not be joining a group or not being accepted by a group, so awareness can be a reason; capacity building at various levels such as accounts, understanding the roles of group, planned strategy of the group with objectives, short and long term goals are needed; promote transparency – there may be vested interests for example, for not showing the accounts, so a democratic function and rotation of presidentship can be useful.

Second Session – Twin track approaches to ensure equal opportunities for people affected with leprosy, session coordinator *Wim van Brakel*. Wim introduced the concept of twin-track approach. These were followed by some presentations.

Specific issues and challenges of inclusion of people with leprosy related disability in general CBR programmes and vice versa, Jose Manikkathan: He explained the main approach of AIFO/Italy of working with marginalised groups including leprosy affected persons, disabled persons, etc. SHGs are the entry point for self development and rehabilitation. Attitude change is needed among service providers, disabled persons, family members and community. Often persons affected by leprosy are excluded from CBR programmes. He explained the change in AIFO's support, from vertical programmes to community-based integrated programmes including rehabilitation. It started in 1992. All leprosy programmes were asked to work with CBR and in all CBR work must include leprosy. Important lesson is to avoid starting parallel NGO-based services; rather it is important to increase the potential of existing services, including Government

services. By bringing together different stakeholders including civil society, government and disabled persons, big changes can be produced in the communities.

Mainstream micro-credit for people affected by leprosy, Prakash Wagle: He works in western part of Nepal. Their INF project started as an out-reach programme in 1975, and CBR was started in 1997. It is open to all different groups of persons with disabilities. Micro-credit, the main project strategy, can be in monetary grant, loan, seed capital or revolving funds, etc. A large loan given thoughtlessly can create a burden. INF works with leprosy affected persons, community-based organisations (CBOs), non-governmental organisations (NGOs), SHGs, etc. They tried to work with bank but banks do not want to work with disabled or leprosy affected persons and require collateral or group guarantee. They also asked a bank to take funds, and give loans to people, but bank said we will not cover any risks, so it has not been yet done. So they tried it with a non-governmental development organisation (NGDO) like forestry group. It agreed to collaborate but awareness-raising was necessary. Forestry organisation is also promoting CBR in that village. Now 12 forestry groups doing this, and also provide credit. Many NGOs are also involved in credits so INF does advocacy with them. Important to add that groups do not just get credits, they also need to save. Poor persons are afraid to take money, as they lack training opportunities and self confidence. INF works with 300 groups.

Additional factors of vulnerability among leprosy affected persons influencing integration, Mani Mozhi Natrajan: He started with a story about a child who was not diagnosed for leprosy and treated, till "experts" came from outside to confirm the diagnosis, as asked by leprosy guidelines. Gender, children, elderly, refugee, ethnic clashes, inaccessible area along with low or no priority for leprosy, can create additional vulnerability. A widow, who is poor, and who faces religious sanctions, faces barriers for accessing services. Children going to schools, especially at time of exams, also face barriers. There are children who are not going to school, children from tribal areas, children with disabilities like the cerebral palsy – when they have leprosy, they all face additional problems. Elderly persons with leprosy also face additional problems, as their needs are often ignored. Sometimes, being rich is also a barrier, as for them it may be difficult to access proper government services and in private services, they may spend lot of money but do not get proper treatment.

Twin track approaches: experiences from Bangladesh, Timor Leste and DRC, **Bob Bowers and Angelika Piefer**: In Bangladesh, the leprosy programme supported by TLMI works with more than 500 groups in 4 districts with a total of 7 million population and 42,000 ex-patients, including about 4-5,000 persons with grade 2 disability. They have defined poverty line on the basis of energy consumption less than 2030 Kcal per day, for identifying persons with priority needs.

They did a study on 187 groups with 2000 persons. About 70% of members are leprosy affected persons or family members. They had change of staff and took persons who could have facilitation and empowerment skills. Groups were given seed funds and 50% group members were in management committee. Many indicators show that they are now doing advocacy and promoting change. 30 % of leprosy patients have disability.

Persons affected with leprosy face two cycles of poverty – disability and poverty, plus stigma and poverty. Flexibility and different approaches are needed. The issue is if nothing is there, what do you mainstream to? Examples were presented from D. R. of Congo,

Thailand, Papua New Guinea, East Timor, etc. Exit strategies with group need to be considered from the beginning.

Group Discussions

Cooperation between ILEP and other disability organisations – Group discussions were facilitated by Janine Ebenso. Group felt that it is easier to share information, magazines, invite each other to trainings, workshops, etc. with other organisations. Projects supported by ILEP member need to work with others to have a common strong voice towards inclusion, empowerment, sustainability.

Facilitating further involvement of organisations of persons affected by leprosy in rehabilitation/CBR – Group discussions were facilitated by Mohammad Aleem Arif. The group was not sure about the exact terms of discussion and they had initially discussions about understanding the question. The issues that came up during the discussions included – advocacy by existing groups for inclusion; encourage networking between Disabled Peoples' Organisations (DPOs) and CBR; transition from the donors to specialised leprosy specific activities to support for more generalised activities; advocate policies and guidelines based on UN Convention on Rights of Persons with Disabilities (CRPD); capacity building of leprosy DPOs; there should be baseline data on different disabilities.

Promoting leprosy affected persons to be members of SHGs – Group discussions were presented by Rens Verstappen. The group suggested creating awareness that SHG exist and generate some enthusiasm; there should be clear objectives, and related to this issue there was some discussion in the group about who should set the objectives & the issue of participatory planning. Some persons in the group felt that SHG members can formulate the objectives themselves, after their formation. Capacity building of SHG members should be on the basis of a needs assessment with help of external facilitators.

A four track approach was suggested – depending upon the context, best approach can be the inclusion of general disabilities & leprosy disabilities in the SHGs; some times, temporary leprosy specific groups may be needed; SHGs need internal criteria and rules, they need to inform and/or involve local authorities.

Integrated rehabilitation when leprosy affected persons live scattered in the communities and villages where is no existing CBR approach and funds are limited, the Group discussions were presented by Nevis Mary. The group looked at different options including – individual approach; sensitizing policy makers; capacity building of all stakeholders including health workers and persons affected by leprosy; outreach approach; twin track approach, mainstreaming and services; advocacy for local groups and persons; respond to most immediate needs; multi-disciplinary approach; good partnership and accountability.

Promoting of combined services for people with leprosy together with other persons with similar needs, the Group discussions were presented by Silatham Sermrittirong. The Group suggested the following – teaching should be given to mainstream and general system about leprosy, it can reduce stigma, but this could increase workload and result in giving less attention to leprosy. Twin track approach in services is possible and there are many existing examples of leprosy services combination with other diseases like TB, dermatology, neglected tropical diseases, etc. Surgeries can be easily

combined with other services; CBR and SER, legal issues, prostheses can be easily combined with other services, stigma reduction for leprosy can be combined with similar work related to mental illness etc.

Stimulating integration of CBR in general development, Group discussions were presented by Sukhlal Singh. The Group felt that persons with disabilities should be involved in the planning of activities. Networking among CBR programmes is needed before going to development programmes. Linking of resources for different programmes is a key issue. Advocacy to the government structures that look after development staff and programmes is needed. So capacity building of government staff, CBR staff, NGOs, etc. is required.

Third session: WHO's CBR guidelines and their implications for the persons with leprosy related disabilities. This session coordinated by *Sunil Deepak* started with presentations.

Implications of WHO CBR Guidelines for leprosy programmes and organisations such as ILEP member associations, by Chapal Khasnabis. He explained that the CBR Guidelines are in the final phase of completion, so that outputs from this workshop can be added to its relevant chapters. WHO is promoting the PHC approach to answer the health needs in a global way. The Joint Position Paper on CBR by different UN agencies also applies to leprosy related work. The Technical Guide on Leprosy and CBR produced jointly by ILEP and WHO is another useful instrument for persons working with leprosy affected persons. Thus community-based approaches have important relevance for leprosy related work.

Poverty is a major issue that nullifies health, education, social and other rights of persons. There has been development of different models of disability from medical to social to human rights. All these models are applicable when we think of rehabilitation needs of persons affected with leprosy and can be applicable in different ways in different phases of work. CBR matrix also applies to leprosy related work. He concluded with information about the specific chapter on leprosy in the CBR Guidelines.

Leprosy programmes adopting the CBR approach: successes and challenges, by Maya Thomas. She explained that CBR matrix and Guidelines are an endorsement of the work already carried out by CBR programmes over the past decades. The issues of service delivery and accessibility are very important, where CBR plays a facilitating role in mainstreaming. CBR can support empowerment and the SHGs in many programmes dealing with leprosy affected persons are like DPOs that are supposed to have at least 51% of the decision making role by the users.

The challenges of applying CBR approach in leprosy work include the difficulty to change from service delivery mode, difficulties in change of mind sets, lack of knowledge about community work, lack of support from donors and policy makers, etc.

There are challenges at the community level where persons want to continue being beneficiaries rather than participants. At the same time, there have many success stories in applying CBR approach in leprosy related work, especially where programmes had a community health departments and were already involved in community prevention of disabilities activities. They have expanded the scope of their work at community level and have the advantage of having hospital services that work as referral services for CBR work

at community level. This is a strength of many leprosy programmes that they can work at community level and at the same time provide good referral level support.

She felt that though these challenges had been raised and discussed many times for the past 7-8 years, but progress in this direction has been limited.

Leprosy and CBR in Thailand, by Jintana Vorasayan. She explained that now there is only one leprosy colony in the central part of Thailand and a CBR model has been pilot tested since 1999-2000 as a health systems research project in 2 villages. This project had a preparatory phase, an 18 months implementation phase and a final evaluation phase. The project worked with persons having leprosy related disabilities as well as other disabled persons. They found that persons affected with leprosy are a small part of all the disabled persons and communities lack information about leprosy related disabilities. It was found that community approach improved the intervention for leprosy affected persons and it would be necessary that all health staff has skills in community participation.

Role of persons affected with leprosy and their organisations such as IDEA in the transition from disease focus to human rights approach, by Nevis Mary. Nevis brought out the voices of different persons with leprosy related disabilities focusing on how it is closely linked to prejudices and stigma, leading to isolation, deprivation and poverty. Through her own personal experience, she explained the importance of livelihood and empowerment in breaking the circle of poverty, exclusion, stigma and discrimination. She advocated for a stronger role of leprosy affected persons and their organisations in different activities of leprosy programmes that promote empowerment at the same time and are more effective and credible, and help in reaching other leprosy affected persons. She explained the experiences of setting up a National Forum of persons affected by leprosy in India and other initiatives that are bringing together persons affected by leprosy, providing new opportunities for them for raising their voices.

Group Presentations

Group 1, Promoting changes of integration and inclusion in existing leprosy specific rehabilitation centres and services. The discussions were facilitated by Hiroe Soyagimi. The Group came up with many positive examples of how leprosy rehabilitation centres and services are moving on the areas of inclusion and integration. A distinction was made – inclusion is holistic while participation is more at individual or personal or organisational level.

The positive examples from different countries included the following – in Vietnam they changed the name of leprosy rehabilitation centre and colony, broke the wall and opened it to all people, so it is more like a village; in Thailand, integration started almost 50 years ago when persons were moved out of leprosy villages; Fontilles in Spain is including other persons with disabilities; in Cambodia, leprosy affected persons are joining and collaborating with other persons in disability movement; AIFO's work in India is integrating all the different groups of persons with disabilities including leprosy related disabilities; in Bangladesh, leprosy is included in general hospital; in Papua New Guinea, PHC staff has been trained to work with different disabilities including leprosy related disabilities. It was felt that there is an issue of capacity building of general health staff and more resources are needed for this.

Group 2, Participation and inclusion – rights based approaches and persons affected with leprosy. The discussions were facilitated by P. K. Gopal. The issues raised in this discussion included the following – change in mind set and practice is needed among the service providers including the government sector, and their skills should be improved; persons affected with leprosy should be included in policy making and decision making; educate disabled persons organisations (DPOs) about needs of leprosy affected persons and ask for due representation; disseminating best practices and role models is useful for educating community; persons affected with leprosy need opportunities otherwise nothing will change; in India there is largest number of leprosy cured persons and there are about 700 leprosy colonies, a national forum has been formed and activities like management skills are organised; in India persons affected with leprosy gave a petition to Government of India and a parliamentary commission visited different leprosy colonies and met with persons, as a result a process has been started to change the 27 discriminatory laws; legal system also needs to be sensitized as sometimes judgements of the courts go against human rights of persons affected with leprosy; all stake-holders including CBR initiatives need to be informed about leprosy-related issues; networking with other organisations is needed; there should be more sustained activities through out the year and not just around world leprosy day; and, equal opportunities are needed for women as they face greater discrimination.

Group 3, CBR programmes – participation and inclusion of persons affected with leprosy. These discussions were facilitated by Sarmila Shrestha. The discussions of the group raised the following issues: we need to get information and people want to give information, so we need to know who is doing what, providing which services, etc.; group formation, forming organisations, networking need more reflection as if only one representative person participates, then voice can not be raised and greater participation is needed; more participatory decision making is required; a change of policy is needed so that persons affected with leprosy are obliged to be included in decision making; it is important to promote change of mind set of health staff and they require capacity building on these issues; finally, mainstreaming is not just going to other services but we also need to mainstream by opening our services to others.

Group 4, Process of empowerment and overcoming barriers of self-stigma. This discussion was facilitated by Anna Kateriina Koch. The discussion raised the following issues – the information about the diagnosis when it is given to the person is a key moment and needs adequate support and time so that the person gets an opportunity to talk about it and counselling is given, that may also involved family members; sharing of experiences and speaking about them is important in the process of empowerment; role models and famous persons can play an important role in creating awareness and promoting empowerment; community level advocacy is important so that persons can access all community spaces such as temples and churches; having skills and jobs is important for empowerment of individuals, as then they need not depend upon others for every thing; providing correct information about leprosy in the community and in the media is important; publicly being together with leprosy affected persons in the community, walking together with them, touching them, eating together with them are important ways and strong messages to show others, and if leprosy and CBR staff and volunteers can do it, their awareness and education activities will have greater impact in the community.

Group 5, Measuring impact of socio-economic rehabilitation activities. This discussion was facilitated by Kamraj Devapithachai. The discussion considered that the SER activities are very broad including social acceptance, economic, marriage, income,

equal opportunities, dignified social life, having choice in deciding, etc. so it decided to focus its discussions about the principles that should inform the measurement of impact. The principles include – starting with positive expectations; standards and baseline information are needed; there should be participation of users at all levels.

Group 6, Transformation from leprosy specific work to CBR open to different persons with disabilities. This discussion was facilitated by Pravat Chandra Barua. The challenges in the transformation raised by the group included – lack of clear cut government policy in many national leprosy programmes regarding CBR; service delivery model that is in place for leprosy control programmes, is not conducive to CBR; the mindset of being providers and not facilitators becomes a barrier in moving towards community-based approaches and programmes; DPOs of leprosy affected persons may not be in favour of opening services to other persons with disabilities as they may fear that resources will decrease for them; there is a lack of awareness in the health sector about CBR approach; there is lack of information and lack of recognition about leprosy cured persons, who have disabilities and other needs; beneficiaries themselves may feel threatened by the change and ask for continuing the old way of services; stigma towards leprosy affected persons among other disabled persons can be a barrier against their participation; a practical difficulty is that CBR comes under two different ministries, health and social security, so implementing a programme is difficult; evidence based practices are needed so more health systems research and action research on CBR and Leprosy is needed.

Final Session – Summing up and the Way Forward. *Douglas Soutar* coordinated this session.

Mr. Soutar explained that we need to collect ideas from these discussions, to bring together the key principles, priority areas for action and to come up with framework for action and the next steps and some mechanism that those steps are followed up, to take back to ITC and ILEP.

Inclusion of needs of leprosy affected persons – principles and priorities for action. A presentation by Wim van Brakel. His presentation touched on the following points:

Principles of CBR – Inclusion, participation, self-advocacy, self-sufficiency (choice, having livelihood, being able to live with dignity...), equity (equality, equal opportunities same as others, not more than them and not less), empowerment, social justice (including the areas of rights).

Operational conditions for success of CBR – need based services, participation of disabled persons and community at all levels, multi-disciplinary teams, adequate expertise of staff so ensuring good training, awareness of our own limitations and referring when necessary, complementary to development services and specialist services.

Priority areas of action – inventory of existing services as first step only then look at needs so that at the same time, you can already provide information (use what already exists), lobby for integration of leprosy related disabilities in mainstream services, promoting reverse integration by reaching persons with other disabilities, implications of human rights perspective (including structural discrimination and dis-empowerment, also in own organisation), increased attention to environmental and personal factors, research.

Future work

Hugh Cross presented the modified nominal group technique and his analysis of the priorities expressed in the group discussions. For each group discussion, Hugh explained the different variables that came out of this analysis. For example, in some groups, very high mean scores came out showing that there was little consensus among the group members, in other groups there was more consensus.

Following this, the group of participants jointly identified some themes for future work and for each theme a reference person was identified. The identified themes were as follows (with each theme, the name of the person who volunteered to follow it, is indicated):

- Inclusion and opportunity to participate: Understanding the processes, challenges, preparation & training needs and implications of promoting inclusion of persons affected with leprosy in general CBR programmes and enlarging the scope of leprosy specific rehabilitation services to persons with other disabilities. (Sheikh Abdul Hadi)

- Finance and resource allocation: The twin-track approach of integration and inclusion between CBR and leprosy, as well as adopting the different areas of CBR matrix require preparation, capacity building and adequate resources. (P. K. Gopal)

- Collaboration-coordination: There is need for greater collaboration and coordination in the field in the countries where different ILEP member organisations are working, to learn from each other and to support each other. (ILEP secretariat)

- Facilitation: The term can be understood in different ways, how CBR approach learning can be facilitated, how persons and programmes facing challenges can find advice, how the group together can continue a learning process. (Janine Ebenso)

- Networking: There is need to network with other disability and development organisations at national, regional and international levels so that mainstreaming of needs of persons affected with leprosy occurs and at the same time, organisations and programmes working in leprosy can learn and strengthen their work. (?)

- Rights based approach: After the approval of the United Nations Conventions on Rights of persons with disabilities and the leprosy related initiatives of UN Commission on Human Rights, there is greater awareness of the Rights-based approach but there is not enough understanding about translating this approach into practical daily work of leprosy services. (Douglas Soutar)

- Evidence: While there are growing numbers of experiences of inclusion and integration between leprosy and CBR in different countries of the world, there is not

enough work on collecting evidence about different approaches and strategies used in the field and their advantages and limits. (Johan Velema)

- Appropriate terminology: Persons affected with leprosy and their organisations are asking the organisations and professionals to review the leprosy related terminology used in the field. (Wim van Brakel)

- CBR-CBD links: The issue of links between community-based rehabilitation (CBR) and community-based development (CBD) is much wider and needs to be seen in context of different disabilities including its implications, needs, processes, etc. for rehabilitation needs of persons affected with leprosy. (Isaac Gnanapragasam)

Closing remarks

Mr. Chapal Khasnabis, Dr Myo Htoon, Mr. Douglas Soutar and Dr. Sunil Deepak thanked all the participants for their active participation and made closing remarks about the work and issues discussed during the workshop.

It was agreed that while there are many challenges facing the integration-inclusion of CBR approach & programmes on one hand, and on the other hand, specific rehabilitation centres and services related to persons with disabilities due to leprosy, still the workshop was important in the sense that it did not limit itself to identification of challenges and making recommendations. A large number of positive examples of how this "inclusion-integration transformation" is taking place in programmes supported by ILEP member organisations, were presented, that can guide future developments.

Availability of tools that can help, including the WHO and ILEP joint publication on CBR and the forthcoming WHO CBR Guidelines, is another important support in promoting this transformation.

Still, only a limited amount of information was available about the significance and impact of CBR-leprosy interface. Though some scientific review of this work has been done, it is not yet shared with others and much more can be done in this direction.

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Annex 1

COMMUNITY-BASED REHABILITATION (CBR) AND PERSONS AFFECTED WITH LEPROSY

International Workshop, Bangkok, 21 – 22 February 2009

Promoted by WHO/DAR, WHO/GLP, ILEP, IDEA, National Leprosy Programme- Thailand

FINAL LIST OF PARTICIPANTS

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06	**China**	Ze Fang	Wu
07		Zhi Qiang	Chen
08		Xiu	Li Qi
09		Warren H.	Choi
10		Marianne	Rizzi
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12		Angelika	Piefer
13	**Ghana**	George	Abram
14	**India**	Jose	Manikkathan
15		Jayanth	Kumar
16		Alice	Joseph
17		Aley	Chinothuvattukulam
18		Manimozhi	Natarajan
19		Myo Thet	Htoon
20		Sumana	Barua
21		Mohammad Aleem	Arif
22		Ghanshyam	Dikshit
23		P.K.	Gopal
24		Maya	Thomas

25		Lourdes N Mary	Irudayaraj
26		M.	Srinivasulu
27		Sudhakar	Bandyopadhyay
28		Isaac	Gnanapragasam
29		Kamraj	Devapitchai
30		Ranga Nadh	Rao
31		Atul	Shah
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39	**Japan**	Hiroe	Soyagimi
40		Takechi	Masato
41	**Myanmar**	Tin	Shwe
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43		Parvati	Oli
44		Krishna Prasad	Dhakal
45		Nandlal	Banstola
46		Sukhlal	Singh Budhathoki
47		Prakash	Wagle
48		Ramesh	Choudhary
49		Madhusudan Sharma	Subedi
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51		Wim	Van Brakel
52		Rens	Verstappen
53		Carin	Rensen
54		Jan Willem	Dogger
55		Johan	Velema
56		Daan	Ponsteen

57	**New Zealand**	Andrew	Harding
58	**Nigeria**	Jannine	Ebenso
59	**Philippines**	Hugh	Cross
60		Istvan	Patkai
61	**Spain**	Fatima	Moll Cervera
62	**Swizerland**	Chapal	Khasnabis
63	**Thailand**	Wolfang	Kampf
64		Somchye	Rungtrakulchai
65		Krisada	Mahotarn
66		Silatham	Sermrittirong
67		Jintana	Vorasayan
68		Gomes	Unarat
69		Achara	Chullaprahm
70		Siramas	Rodchan
71		Songkran	Poopook
72		Supayada	Sangsomruang
73		Chanya	Phuklan
74		Vijitra	Thareesuwun
75		Somkiet	Mahaudomporn
76		Saowanee	Bamphenyu
77		Chatchada	Srichupium
78		Kissawat	Somwang
79		Rujira	Tragoolpua
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81		Sangrawce	Ratsamehan
82		Pojana Tcharyaki	Hikul
83	**UK**	Douglas	Soutar
84	**Vietnam**	Thu Hien	Le
85		Jan	Robijn
86		Anna Kateriina	Koch

Annex 2

WORKSHOP PROGRAMME
COMMUNITY-BASED REHABILITATION (CBR) AND PERSONS AFFECTED WITH LEPROSY

Saturday 21 February 2009	
08.00	**Registration**
08.30	**Inauguration** • Chapal Khasnabis, WHO/DAR • Krisada Mahotarn, MoPH, Thailand • Sumana Barua, Leprosy WHO/SEARO • Douglas Soutar, ILEP
09.00 – 13.00	**Session 1** Coordinator *Hugh Cross, Philippines* **The evidence base for CBR in relation to leprosy: experiences:** This section would focus on practical examples, both positive and negative, of how the transition has been or can be made from treatment and care to the promotion and facilitation of empowerment. This is very much about giving up control and changing roles of service providers from 'experts' to 'facilitators'. 09.00 – 10.30 Plenary session Backbone Principles of the new CBR guidelines: shaping the future of Rehabilitation in Leprosy, *Johan Velema, Netherlands* Measuring impact of micro-credit schemes and income generation, *Issac Gnanapragasam, India* Development of leprosy SCGs to multi-disability SHGs – a case study, *Ramesh Chaudhary, Nepal* Assessment of disability in Nepal, *Madhusudan Subedi, Nepal* 10.30 – 11.00 Coffee break 11.00 – 12.00 Discussions in small groups Group 1: How to ensure quality of care/rehabilitation in a multitude of self-care or self-help groups and monitor their progress? *Facilitator: Jayanth Kumar, India* Group 2: Methods and tools for empowering people with disability (improving self-efficacy) - *Facilitator: Ranganadh Rao, India,* Group 3: What indicators to use for outcome/impact assessment *Facilitator: Carin Rensen, Netherlands*

	Group 4: What methods can be used to assist health workers to accept and encourage the transference of the locus of control from health professionals to disabled people - *Facilitator: Andrew Harding, New Zealand* Group 5: What are the most appropriate ways to resolve conflicts and to promote cooperation amongst self-help group members? - *Facilitator: Michael Chen, China* Group 6: What are the main threats to the success or development of self-care or self-help groups and how can these be addressed. - *Facilitator: Manimozhi Natarajan, India* 12.00 – 13.00 Plenary session: Presentations of group discussions by facilitators followed by discussions
13.00 – 14.30	**Lunch Break**
14.30 – 18.30	**Session 2** **Twin-track approaches to ensure equal opportunities for people affected by leprosy** Session coordinator *Wim van Brakel, Netherlands* Integration: experiences of how leprosy affected people are or can be included in wider CBR programmes and how other disabilities can be included in leprosy related CBR work. Inclusion in mainstream development programmes: This is an extension of the *Integration* topic in that it broadens the issue even further to look at how people with leprosy related disability and people affected by other disabling conditions and discrimination can benefit from mainstream (development) programmes. Inclusion then takes us beyond "combined CBR programmes" to consider how all people with leprosy related or other disabilities or discrimination can be included into the mainstream development processes relating to health, education, livelihood, human rights etc. 14.30 – 16.00 Plenary session Specific issues and challenges of integrating people with leprosy-related disability (PLD) in general CBR programmes and vice versa. *Jose Manikathan, India* Mainstream micro-credit for people affected by leprosy, *Prakash Wagle, Nepal* Additional factors of vulnerability among leprosy affected persons influencing integration, *Manimozhi Natrajan, India*

	Twin-track approaches: experiences from Bangladesh, Timor Leste and DRC, *Angelika Piefer, Congo & Bob Bower Bangladesh* 16.00 – 16.30 Coffee break 16.30-17.30 Small Groups discussion Group 1: How to cooperate with ILEP members and other disability organisations in a given country? *Facilitator: Jannine Ebenso, Nigeria* Group 2: How to facilitate involvement of organisations of people affected by leprosy in rehabilitation/CBR? *Facilitator: Mohammad Aleem Arif, India* Group 3: How to promote/facilitate formation of self-help groups and organisations? Should PLD be encouraged to form leprosy-specific groups and organisations or to join general DPOs? *Facilitator: Rens Verstappen, Netherlands* Group 4: What to do regarding integrated rehabilitation in situations where people with leprosy related disabilities live scattered in the country and coverage of CBR programmes is very incomplete? What to do about the tension between supporting a multi disability approach on a small(er) scale, versus a leprosy only approach on a large scale when funds are limited? *Facilitator: Nevis Mary, India* Group 5: Is there scope for promoting combination of services for people with leprosy related impairment and/or disability with those of others with similar needs (e.g. people with diabetes, lymphatic filariasis, etc.) or is it counterproductive to real integration? *Facilitator Silatham Sermrittirong, Thailand* Group 6: What does integration of community based rehabilitation into general development programmes and activties means in practice and how can it be stimulated? *Facilitator: Sukhlal Singh, Nepal* 17.30 – 18.30 Plenary session Presentations of small group discussions by facilitators and discussions
End of day 1 of workshop	
Sunday 22 February 2009	
09.00 – 13.00	**Session 3** Coordinator *Sunil Deepak, Italy* **The application of the WHO-CBR Guidelines for development of rehabilitation services in leprosy work:** An analysis of the application of the WHO-CBR Guidelines for

	for leprosy programmes and organisations 09.00 – 10.30 Plenary session Implications of WHO CBR Guidelines for leprosy programmes and organisations such as ILEP member associations: *Chapal Khasnabis, Switzerland* Leprosy programmes adopting the CBR approach: successes and challenges, *Maya Thomas, India* Leprosy and CBR in Thailand, *Jintana Vorasayan, Thailand* Role of persons affected with leprosy and their organisations such as IDEA in the transition from disease focus to human rights approach, *Nevis Mary, India* 10.30 – 11.00 Coffee break 11.00 – 12.00 Discussions in small groups Group 1: Leprosy rehabilitation centres and services – challenges of integration and inclusion, *Facilitator Hiroe Soyagimi, Japan* Group 2: Participation and inclusion – right based approaches and persons affected with leprosy, *Facilitator: P. K. Gopal, India* Group 3: CBR programmes: partecipation and inclusion of leprosy affected persons, *Facilitator: Manimozhi Natarajan, India* Group 4: The process of empowerment & overcoming the barriers of self-stigma, *Facilitator Zhi Qiang Chen, China* Group 5: Socio-economic rehabilitation – measuring impact *Facilitator Isaac Gnanapragasam, India* Group 6: Leprosy and human rights, *Facilitator: Kamraj Devapitchai, India* 12.00 – 13.00 Plenary session: Presentations of group discussions by facilitators followed by discussions
13.00 – 14.30	**Lunch Break**
14.30 – 17.30	**Session 4:** Coordinator Douglas Soutar **Principles for inclusion of needs of Persons with Leprosy related Disabilities into CBR** Establishing key principles as well as a framework for action to be taken in leprosy rehabilitation programmes and services in response to the direction provided by the WHO CBR Guidelines

	Plenary session 14.30 – 17.30 (with coffee break at 15.30) Principles and priority areas for action - Wim van Brakel (30 Min) Tasks and Prorities – Nominal Group technique coordinated by Hugh Cross for defining tasks and priorities for future action, next steps to be defined and a mechanism to follow this up.
17.30 – 18.00	**Conclusions and closure** Chapal Khasnabis, WHO/DAR Sumana Barua, SEARO/Lep Sunil Deepak, ILEP/ITC