SERIES NO. 6

LEAP

LEPROSY
ELIMINATION
ACTION
PROGRAMME

OCT 15

TASK TODAY

Stigma and Discrimination : Strategies and Guidelines

Leprosy Laws and Acts : Response of Government

Leprosy and Human Rights : Entitlements of Persons Affected

ALERT-INDIA'S
37th FOUNDATION DAY
SPECIAL ISSUE

INDEX

Foreword : The solution to a problem does not lie in the same paradigm

Preface : End prejudices and exclusion : ensure rights of PALs

I. Stigma and Discrimination 3

(1) Strategies to Eliminate Stigma and Discrimination in Leprosy under NLEP

(2) Elimination of discrimination against persons affected by leprosy and their family members - principles and guidelines

(3) Understanding the Stigma of Leprosy

(4) Partnership approach to stigma reduction

(5) Approach to tackling stigma in leprosy

(6) Leprosy rehabilitation : decentralized and community-based strategies

II. Leprosy Laws and Act 19

(7) Antiquated Acts on Leprosy - Amendments proposed and Action Taken Report (ATR)

(8) Eliminating discrimination against Persons Affected by Leprosy - A proposed Bill

(9) The Rights of Persons with Disabilities (RTD) Bill, 2014

(10) The position in International law could not be clearer : no discrimination

(11) A critical analysis of various legislations and policies on disability in India

(12) Where does Indian disability Law stand in the present International scenario?

III. Improving quality care : prescriptions 43

(13) Protect and Promote the Human Rights of People Affected by Leprosy

(14) Deendayal Disabled Rehabilitation Scheme to promote Voluntary Action for Persons with Disabilities (Revised)

(15) Integration and empowerment of leprosy affected persons - Response from the Government

(16) The Right to Health : Obligations of the State

Published by : ALERT-INDIA, B-9, Mira Mansion, Sion (West), Mumbai - 400 022.
☎ 2403 3081-2, 2407 2558 Fax: 2401 7652
e-mail: alert@bom5.vsnl.net.in Web Page: www.alertindia.org

Cover Design : ethos, Mumbai.

The solution to a problem does not lie in the same paradigm

The problem associated with the disease Leprosy are at many levels - medical, physical, emotional, psychological, social and societal. The issues are all interlinked.

I have had the fortune of working with several inspiring individuals who are leaders in the field of Leprosy – medical doctors, heads of NGOs, Government agencies, persons affected by Leprosy each one of them is passionate about alleviating the issues related to poverty, vulnerability, disability and treatment of the disease. Yet, for all the work we have done so far, the solution we are all looking for has not been found as of now. Perhaps the reason for this could be that the solution to a problem does not lie in the same paradigm in which the problem lies.

Since Leprosy is considered to be the disease of the poor, the stakes are not high enough to grab the attention of the mass - as a result of which the impact on the Leprosy affected can be devastating .The disease leaves the individual with a further insurmountable burden – of handicap, of vulnerability to loss of limbs due to ulcer and fractures, to name a few. However, since State does not owe this individual medical or economical rehabilitation, the affected individual along with his or her co-dependents will have to live a life stripped of dignity. Clearly, his or her fate is not the concern of the rest of the society. After all, the Leprosy – affected is not one of 'them'.

The affected individuals from a less rural setting go through embarrassment throughout their lifetime. Attending educational institutions, going to workplace, being eligible for marriage – things that the society's individual takes for granted, becomes now a disturbing reminder of being 'unfit' – being not fit to mingle with the other students, being non-employable and being ineligible in the marriage market.

What we need to alleviate the disease is perhaps innovation. In any area of life that needed transformation, the world has used the contribution of thought leaders, trusted opinion leaders to become spokespersons for the issue leading to benefit for all concerned.

We need to innovate, to reach the tipping point – where ideas that spread like viruses do.

The target of 'Elimination' achieved a certain result. And that result is now a thing of the past. For our future, I believe that we ought to have a new game.

11th October, 2015

Jayashree P Kunju

Trustee, 'GoodBye Leprosy' Trust

Is a CA, and CEO of iBAS Consulting Pvt Ltd, a company providing CFO services.
She was affected by Leprosy as a young undergraduate and works for the cause of Leprosy.

End prejudices and exclusion : ensure rights of PALs

Myths and misconceptions about leprosy affects the social recognition. It is a scourge on account of trouble free nature of leprosy coupled with lack of scientific knowledge both among the health care providers and the community at large. As a result, the social perspective of the health care providers is no different from that of the general public when it comes to prejudices and exclusion and the resultant despicable treatment meted out to PALs till date.

All through the first decade of integration, the General Health Care (GHC) System had remained a hesitant partner in weeding out the backlog of leprosy cases in the routine programme. The GHC System's hard shelled indifference and pathetic inadequacies of today are direct result of the 'historical fallacy' of the 'vertical NLEP decades' that kept an unjustifiable 'extreme aloofness' with the rest of the public health system until ten years ago. Further, the 'general' tertiary health care services are often denied to Persons Affected by Leprosy (PALs) in public health facilities due to lack of knowledge and in case of deformed PALs due to prevailing stigma and prejudice.

The remaining NLEP task force is fatigued and inertia has set in following the integration. In fact, we do not have a foolproof operational strategy to contain the spread of leprosy 'infection' and 'transmission'. New cases continue to occur throughout the country. We lack epidemiological information on locations, actual number of new PALs.

An estimated 2 million backlog of cured patients with disabilities and deformities who may need care and other socio economic interventions and services live in the community and the health care providers remains utterly uninformed about the addition of new deformed and the 'deformity prone' patients.

This issue of 'Task Today' Series-6 focuses on stigma and discrimination related issues that taunt us till today. Issues that are engrained in misbelieves and unscientific legal provisions need to be countered effectively with a positive social dialogue. This requires change in the outlook and enunciation of proactive policies and intervention strategies that cut through the age old prejudice and irrational fear.

It was evident from the start that additional inputs and resources are required to address the problems related to consequences of leprosy during integration phase. There is a dire need to create appropriate support structures and effective referral mechanisms within the GHC system, to make possible sustained quality leprosy services and ensure the rights of people affected by leprosy.

Sion, Mumbai
11th October, 2015

A. Antony Samy
Chief Executive

1

Strategies to Eliminate Stigma & Discrimination in Leprosy under NLEP

Director General of Health Services
Central Leprosy Division,
Government of India, New Delhi - 110 001

In India, over the years, with the introduction of MDT and IEC campaigns, the stigma and discrimination against persons affected with leprosy is gradually coming down; but still there is lot of scope for innovative interventions to eliminate stigma and discrimination, so that persons affected with leprosy are fully integrated with society.

Intervention strategies

Stigma associated with the disease is very deep rooted, evolved through centuries of misconceptions and myths. The process of achieving the acceptance of the leprosy patients in the community along with social status culturally acceptable in the absence of disease/ill health condition should be treated as stigma reduction.

The strategy to reduce stigma in leprosy have to be mainly through spreading awareness. Strategies to reduce stigma must involve active participations between all three i.e. affected people, Health care provider / educator and the community, based on sense of human dignity, equality and acceptance of leprosy affected persons by the community.

Interventions required may be at five levels –Viz. intrapersonal, interpersonal, community, organizational / institutional and governmental level. Stigma reduction programs should use a combination of approaches. Promising interventions are empowerment, counseling, contact with affected persons and education.

Suggested line of action under NLEP

1. The National Rural Health Mission carry out various health related IEC activities including for leprosy. The State and District Programme Officers will coordinate with the respective NRHM IEC cell to incorporate all communication strategies in the NRHM activities.
2. Develop strategy with the involvement of the following six groups of persons

---

Source : *NLEP - Guidelines on reduction of stigma and discrimination against PALs, 2011* such as i) civil societies; ii) social activists; iii) health service providers; iv) community / opinion leaders; v) corporate sector and vi) media as partners to fight stigma against person affected with leprosy.

3. Utilise the Village Health and Sanitation Committee Meeting on “Health Day” to spread specific messages for Behavior Change Communication (BCC) through some of experts in the above groups.
4. Develop and use effective, attractive and impressive communication of destigmatizing messages through different Media agencies.
5. During “Health Mela”, organize care and concern camp with trialogue and dialogues with the aim of combining services (Diagnosis, POD care) with BCC. Such camps organized jointly by community and health department with the purpose of demonstrating in discriminatory behavior and zeroing distances along with providing services and educating the people have been found to give strong impact.
6. Women mobilization for sensitizing about the disease and utilizing their services for awareness generation in villages can be very helpful to reduce stigma.
7. Prepare and implement non-discriminatory behavior guidelines for service providers which include institutions and individuals. Separate leprosy clinic room in PHC/CHC/SDH/ District Hospital to be closed down immediately.
8. Empower the people affected by leprosy to overcome discrimination by supporting “self care group in leprosy colonies. Involve the “Lok Doots” appointed by the National forum of PALs, wherever needed, and support such initiatives.

These are only a few suggested lines of actions. The programme officers at State / Districts may feel free to work out and implement measures to reduce stigma against leprosy and remove discrimination against person affected by leprosy. ■

2

Excerpts

Elimination of discrimination against persons affected by leprosy and their family members - principles & guidelines

Secretary General
United Nations General Assembly
Human Rights Council, Geneva, Switzerland

I. Principles

1) Persons affected by leprosy and their family members should be treated as people with dignity and are entitled, on an equal basis with others, to all the human rights and fundamental freedoms proclaimed in the Universal Declaration of Human Rights, as well as in other relevant international human rights instruments to which their respective States are parties, including the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights, and the Convention on the Rights of Persons with Disabilities.

2) Persons affected by leprosy and their family members should not be discriminated against on the grounds of having or having had leprosy.

3) Persons affected by leprosy and their family members should have the same rights as everyone else with respect to marriage, family and parenthood.

To this end:

(a) No one should be denied the right to marry on the grounds of leprosy;

(b) Leprosy should not constitute a ground for divorce;

(c) A child should not be separated from his or her parents on the grounds of leprosy.

4) Persons affected by leprosy and their family members should have the same rights as everyone else in relation to full citizenship and obtaining identity documents.

5) Persons affected by leprosy and their family members should have the right to serve the public, on an equal basis with others, including the right to stand for elections and to hold office at all levels of government.

6) Persons affected by leprosy and their family members should have the right to work in an environment that is inclusive and to be treated on an equal

---

Source: *UN General Assembly, 5th Session 2-6 August 2010, A/HRC/15/30 ps. 3-7* basis with others in all policies and processes related to recruitment, hiring, promotion, salary, continuance of employment and career advancement.

7) Persons affected by leprosy and their family members should not be denied admission to or be expelled from schools or training programmes on the grounds of leprosy.

8) Persons affected by leprosy and their family members are entitled to develop their human potential to the fullest extent, and to fully realize their dignity and self-worth. Persons affected by leprosy and their family members who have been empowered and who have had the opportunity to develop their abilities can be powerful agents of social change.

9) Persons affected by leprosy and their family members have the right to be, and should be, actively involved in decision-making processes regarding policies and programmes that directly concern their lives.

Guidelines

1. **General:** States should promote, protect and ensure the full realization of all human rights and fundamental freedoms for all persons affected by leprosy and their family members without discrimination on the grounds of leprosy.

2. **Equality and non-discrimination:** States should prohibit all discrimination on the grounds of a person having or having had leprosy, and should guarantee equal and effective legal protection to persons affected by leprosy and their family members.

3. **Women, children and other vulnerable groups:** States should promote the full development, advancement and empowerment of women, children and members of other vulnerable groups who have or have had leprosy, as well as their family members.

4. **Home and family:** States should, where possible, support the reunification of families separated in the past as a result of policies and practices relating to persons diagnosed with leprosy.

5. **Living in the community & housing:** States should promote the enjoyment of the same rights for persons affected by leprosy and their family members as for everyone else, allowing their full inclusion and participation in the community.

6. **Participation in political life:** States should ensure that persons affected by leprosy, and their family members, enjoy voting rights, the right to stand for election and the right to hold public office at all levels of government, on an equal basis with others. Voting procedures must be accessible, easy to use and adapted to accommodate any individuals physically affected by leprosy.

7. **Occupation:** States should encourage and support opportunities for self-employment, the formation of

cooperatives and vocational training for persons affected by leprosy and their family members, as well as their employment in regular labour markets.

8. **Education:** States should promote equal access to education for persons affected by leprosy and their family members.

9. **Discriminatory language:** States should remove discriminatory language, including the derogatory use of the term “leper” or its equivalent in any language or dialect, from governmental publications and should revise expeditiously, where possible, existing publications containing such language.

10. **Participation in public, cultural and recreational activities:** States should promote access on an equal basis with others to public places, including hotels, restaurants and buses, trains and other forms of public transport, cultural and recreational facilities, places of worship for persons affected by leprosy and their family members.

11. **Health care:** States should provide persons affected by leprosy at least with the same range, quality and standard of free or affordable health care as that provided for persons with other diseases. In addition, States should provide for early detection programmes and ensure prompt treatment of leprosy, including free medication, treatment for any reactions and nerve damage that may occur, psychological and social counselling in order to prevent the development of stigmatic consequences.

12. **Standard of living:** States should recognize the right of persons affected by leprosy and their family members to an adequate standard of living, and should take appropriate steps to safeguard and promote that right, without discrimination on the grounds of leprosy, with regard to food, clothing, housing, drinking water, sewage systems and other living conditions.

13. **Awareness-raising:** States, working with human rights institutions, non-governmental organizations,civil society and the media, should formulate policies and plans of action to raise awareness throughout society and to foster respect for the rights and dignity of persons affected by leprosy and their family members.

14. **Development, implementation and follow-up to States’ activities:** States should consider creating or designating a committee to address activities relating to the human rights of persons affected by leprosy and their family members. The committee should ideally include individuals affected by leprosy and their family members, representatives of organizations of persons affected by leprosy, human rights experts, representatives from the human rights field and related fields, and representatives of government. ■

3

Understanding the Stigma of Leprosy

Edward Eremugo Luka
PHC Advisor, Sudan Health Transformation Programme, Sudan

Definition of stigma

The commonly used definition of stigma is “the attribute that is deeply discrediting” and “that reduces the bearer from a whole and usual person to a tainted, discounted one”. Another definition states that stigma is “a social process that exists when elements of labelling, stereotyping, separation, status loss and discrimination occur in a power situation that allows them”.

Stigma can be classified into three types:

- **Enacted** - the commonest type in which there are actual experiences of discrimination.
- **Perceived** - stigma viewed from the perspective of the patient. It is “the devaluation, shame, secrecy and withdrawal triggered by applying negative stereotypes to oneself”.
- **Self stigma** - the fear of being discriminated against.

Stigma process

Understanding how stigma develops is crucial for planning strategies to reduce it Stigma associated with leprosy does not start immediately after the disease starts, but develops over time in 2 stages:

Stage 1 - the cognitive dimension. This describes how much influence the disease has on the person’s life. The patients pass through the concealability course, disruptive, aesthetic, origin and peril dimensions.

Stage 2 - the affective stage in which the social devaluation of the individual occurs. People with leprosy go through two stages in coping with their condition: the concealment phase and the exposure phase. In moving from one phase to the other, there are triggers to exposure and discrimination such as the visible signs of the disease. However, in the process, stigma enforces the inequalities that are found in the community with regards to gender, age and social class.

Source: *South Sudan Medical Journal, August 2010*

The impact of stigma

Having a stigmatizing disease like leprosy severely affects aspects of life such as social status, employment opportunities or jobs, marriage and family life. These can be summarized as effects on:

- the individual
- the community
- public health programmes and interventions.

Effects on the individual

The impact of the meaning of the disease may be a greater source of suffering than symptoms of the disease. Individuals with leprosy have emotional stress and anxiety, which may lead to psychological and psychiatric morbidity, as well as a decreased quality of life. They become isolated and lack motivation to continue treatment (if already started).

There is a risk that the disease will progress with resultant disability and complications. Individuals may have decreased status in the community because of their conditions. In the case of leprosy they may become destitute and resort to begging as the only way of survival. These effects are greater in female than male patients. The women also tend to present late, have complications and disabilities.

Effects on community interaction

The social participation of persons affected by leprosy is much more distressing to them than their individual effects. It impairs their quality of life in various ways.

Persons with stigmatizing conditions experience problems in their marriages or difficulties in getting married and in their employment or getting employed. Their community interaction is affected, such as social relationships and friendships. Their families may experience reduced educational opportunities, leading to further inequities between those affected and those who are not.

All of these negative effects result from poor community knowledge of the disease, and the misconceptions held about them.

Effects on public health programmes

The impact of stigma on public health programmes and interventions have been well documented and discussed. People with the stigmatizing conditions may conceal or deny their condition and delay seeking treatment – which may:

- result in the diseases getting worse and increase the risk of complications
- increase the transmission of the disease in the community.
- make it difficult to trace contacts and those defaulted from treatment.

Some patients may not adhere to treatment when diagnosed especially for treatment that takes a long time, like leprosy. Risk of drug resistance developing is then very high. In general therefore stigma results in an increased burden on the general health services.

Fighting the stigma of leprosy

Fear and stigma are difficult to remove. They can only be dealt with through a combination of strategies. Interventions and strategies that can be use to fight stigma is focused on:

- changing the image of the diseases
- integrating programmes
- rehabilitating patients and
- media campaigns.

These interventions are now used in most leprosy control programmes.

WHO encourages integrating leprosy into the general health service. Leprosy patients should be treated in the same outpatient department as those with any other disease, showing the patients and their communities that leprosy is not a 'different' disease. Different countries are in different stages of implementing these interventions that have been shown to reduce stigma.

Education and media campaigns help to correct false beliefs and raise awareness of new advances. They include information about leprosy and its treatment, context-specific media messages addressing misconceptions and traditional beliefs about leprosy, positive images of leprosy and testimonies of people successfully cured of leprosy.

Physical and socio-economic rehabilitation helps to restore self-esteem and status in the community, and assists patients to find employment. The stigma of leprosy is aggravated by the physical deformities associated with the disease.

So programmes that prevent disabilities developing or identify patients most at risk of developing them, can reduce the effects of stigma. Psychological or physical changes reported by the patients can predict development of participation restriction (i.e. the reduction of their involvement in life situations such as social, economic, civic, interpersonal, domestic and educational domains of daily living). ■

4

Partnership approach to stigma reduction

C.P. Mishra and M.K.Gupta
Department of Community Medicine,
Institute of Medical Sciences, B.H.U., Varanasi

Leprosy and Stigma

Reduction of stigma of leprosy has to be done in partnership to the community and the patient. Following measures can have a positive effect on stigma:

[A] Legislative approach: Architectural correction is needed in the legal instruments to protect the right & dignity of leprosy patients.

[B] Service approach: Focus on following key elements of final push for leprosy elimination:

- Integration of leprosy services into the general health services to improve access to treatment.
- Capacity building to enable general health care staff to diagnose and treat leprosy.
- Improve logistic to ensure adequate stocks of MDT at health centres.
- Change society perception of leprosy and motivate people to seek timely treatment.
- Ensure high cure rate through flexible and patient friendly drug delivery system.
- Simplify monitoring to keep track of progress towards elimination.

Special status of leprosy as complicated feared disease should be removed and it should be ensured that it is treated as just another straight forward curable disease. The newer accompanied MDT approach ensures that patients receive a full course of treatment. It has been adopted because someone close to or important to the patient assumes responsibility for helping him or her to complete a full course of treatment.

- Involvement of NGOs in provision of services in difficult areas is a desired task
- Training of health care workers to be more sensitive and empathetic to leprosy patient's concern. They must be skilled for early deduction and management of leprosy patient and

---

Source : *Editorial, Indian J. Prev. Soc. Med. Vol. 41 No.1& 2,2010*

identification and referral of those with complications.

- Ensuring provisions of to reconstructive surgery and creating awareness about this can have a significant impact on functional status of individual.
- Counselling services are of utmost importance. This helps leprosy patients to cope with their disease and avoid self stigmatization and empower them to face discrimination.
- Adoption of preventive practices and training of leprosy patients may help to prevent further disability and deformity.
- Physical and socio economic rehabilitation is worthwhile in restoring self worth and status in the community and helps them to find employment. Extended support and rehabilitation services should be provided to patients and their families.

[C] Educational approach: It is crucial to change the negative perception of leprosy and encourage patients to come forward for treatment as soon as they note a suspicious skin patch. An effective and attractive campaign should motivate:

- ***People with skin lesions -*** to seek timely diagnosis and treatment;
- ***Health workers -*** to “think leprosy” when examining patients with skin problems;
- ***Community leaders -*** to fight against discrimination;
- ***Community members -*** to accept leprosy as a simple curable disease and encourage people to seek and comply with treatment;
- ***Decision-makers -*** to give their support for elimination and to make leprosy services readily accessible.

The attitude of health professionals can influence how patients and communities perceive leprosy. Educational efforts should be directed towards patients, families, PEER and community members (viz school children, youth, community influencers) and health professions. Empowerment of persons with leprosy is key to success in reducing stigma and raising their self esteem. Educating the leaders and community influencers may affect their decision and allow appropriate information to filter down. Media can play a significant role in changing the image of leprosy. All religious leaders promote messages of love, humanity, kindness, companion, truthfulness etc. Many religions have a social wing to support marginalized section of the community by means of orphanages, charitable dispensaries, hospitals, educational institutions etc. Thus religious leaders a potential force and religious places can be a platform to bring a social change. Empowerment of the persons with leprosy, physical and socioeconomic rehabilitation, and positive attitude of health professionals can contribute significantly in the reduction of stigma due to leprosy. ■

5

Approach to tackling stigma in leprosy

Joy Rafferty
University of Dundee,
United Kingdom

Curing stigma of leprosy - Solutions

It is estimated that about 12 million people living in the world today have suffered from leprosy. Although most of that number will not now have active disease, for many the stigma of leprosy is still real and needs to be addressed. It is simply not enough for the medical profession and society to treat the disease and ignore the patient as a whole person. Many, despite their leprosy being dealt with, are still living a sub existence, mere shadows of their former selves and their true potentials. There are two components of the approach to tackling stigma in leprosy: to help those actually affected by stigma and to prevent stigmatization of others in the future. It will be more satisfactory and efficient to prevent stigmatization than to try to reintegrate patients already rejected.

TREAT LEPROSY LIKE OTHER DISEASES

There is a growing awareness among health professionals involved in providing leprosy care that it does not help to treat leprosy differently from other diseases. A study in India showed differences in attitudes towards leprosy in areas where leprosy treatment was integrated in the local healthcare programme alongside other diseases, compared with areas where it was treated separately.

The social stigma of leprosy was rare amongst patients and in the communities using the integrated approach. Patients in villages with the integrated approach were more open about their disease and willing to discuss it with others. Integration into general health services may have other benefits for patients such as shorter distances to travel for treatment, earlier diagnosis and therefore reduced disabilities.

EDUCATION

As can be expected, stigma is much more prevalent among those who are uneducated. Education needs to be three-pronged, teaching patients, their peers and

Source : *Lepr Rev (2005) 76, 119–126*

young people. It is not enough to educate only patients; their communities need to be educated as well. Education should be tailored to suit the particular community, taking into account local cultural and religious beliefs.

Ideally, a local person aware of beliefs and issues in the area should be the educator as communities are more likely to listen to and believe one of their own rather than an outsider. Education must be easily understandable, addressing real concerns. Sometimes targeting information at a particular group may help, for example village leaders. It is important not to undermine their authority.

Educating the leaders may affect their decisions and allow appropriate information to filter down. Teaching children has a double benefit, as they tend to pass on what they have learnt to their parents, thereby educating the whole family.

CHANGING THE IMAGE OF LEPROSY

One way of changing perceptions of leprosy is by using the media. Leprosy was portrayed as just another disease and people were encouraged to come forward when they developed suspicious lesions. All components of the media were targeted, including radio, TV soaps, music, jingles, billboards, buses and walls posters. Instead of the previous negative portrayals of leprosy on TV, it was shown in a positive light with people being happily cured. These types of campaigns are expensive, but can reach a lot of people and be effective in changing attitudes.

PHYSICAL AND SOCIO-ECONOMIC REHABILITATION

To be accepted in their community, the disabled must be trained to overcome their disabilities and do every day things again. Programmes that teach new skills and trades to people affected by leprosy help this acceptance.

Training may also help to prevent further disability and deformity. Rehabilitation schemes involving training and setting up small businesses have proved successful, with about half the participants being restored to their initial economic status.

It is important to rehabilitate those with leprosy alongside those with disability from other diseases in order to help them reintegrate into their original societies, rather than stay in the confines of a leprosy community. Rehabilitation enables patients to regain their self-esteem.

COUNSELLING

People affected by leprosy may benefit from counselling to help them cope with their disease and avoid self-stigmatization and empower them to face discrimination. Individual counselling, however, can be a slow process benefiting only a few patients because of financial and personnel constraints.

A better alternative may be group counselling. This has been shown to help by ensuring that those affected by leprosy do not feel alone, as well as helping them understand and overcome the damaging effects of stigmatization.

ATTITUDES OF HEALTH PROFESSIONALS

The attitudes of health professionals can influence how patients and communities perceive leprosy. It is assumed that health professionals would have a positive attitude to leprosy. However, this is not always the case as reported some doctors refusing to treat people with leprosy.

This problem needs to be addressed, perhaps with more leprosy awareness training during initial education and as part of ongoing professional development. Healthcare staff are in a respected position in a community and their reaction to those with leprosy can have a major positive or negative effect. For many people with leprosy, it is healthcare professionals that provide that first touch. ■

Stigma in Leprosy

After the isolation policy was abandoned due to the availability of effective treatment, leprosy control programmes in most countries changed to promote a policy in which those affected remained in their own communities. This was often done through Information, Education, and Communication (IEC) campaigns. It is reported that some IEC campaigns aroused public fear of leprosy with frightening educational images. This kind of intervention may help to encourage suspected cases to self-report early; however, at the same time it may reinforce stigma that was already present in the target area.

In the context of promoting human rights, people affected by leprosy were encouraged by related organizations to establish their own associations. Associations of people affected by leprosy are sometimes guilty of producing stigma when they go beyond the fight for justice, equal rights and integration to lobbying for special privileges denied to people with other diseases and to other disability groups. When they do so, they unintentionally reinforce the stigma of leprosy as a separate disease in the mind of the public. People should be helped because they have no other support base; not just because they once had a disease and cured.

Silatham Sermrittirong & Wim H.van Brakel, Stigma in leprosy: concepts, causes and Determinants, Lepr Rev (2014) 85, 36–47

6

Leprosy rehabilitation : decentralized and community-based strategies

Maya Thomas & M. J. Thomas***
*Editor, Asia Pacific Disability Rehabilitation Journal
**Consultant Psychiatrist, Sagar Apollo Hospital, Bangalore, India

Implications for Leprosy Rehabilitation Programmes

Globally, the disability rehabilitation scenario today is at an exciting stage. After many years of effort, the International Convention on Rights of Persons with Disability is in sight, a major step forward, and binding on governments to protect the rights of their disabled citizens.

Leprosy rehabilitation programmes are also using decentralized and community-based strategies such as those adopted by other health and development services. These shifts have in turn led to changes in rehabilitation philosophy and practice, moving from a medical model where prevention and reversal of deformities were the prime focus of interventions, to a psychosocial model with emphasis on inclusion, economic rehabilitation, and access to services and human rights. Interventions in leprosy rehabilitation are beginning to shift beyond traditional prevention, treatment and surgical reconstruction to others such as community-based rehabilitation, socio-economic rehabilitation and formation of self-help groups for affected persons and families.

Shift in philosophy and approach

Traditionally, health care institutions used a 'top-down' approach in service delivery and governance. In some cases the systems became so autocratic that the 'needs' of clients were ignored and they never became empowered enough to choose their goals.

In contrast, 'community- based organizations' do not have highly differentiated structures or systems of communication that are imposed on clients. They use a 'bottom-up' approach that allows client participation in strategy development.

Leprosy rehabilitation programmes until recently, tended to be more institution-

Source : *Lepr Rev (2008) 79, 10–16*

based and top-down. However of late, some of these programmes have started adopting 'bottom-up' approaches, using 'participatory needs analysis', 'participatory decision making' etc. They have started moving from charity based rehabilitation philosophy to an enabling, developmental one, focusing on inclusion, self help and so on. There may be a need for training to build capacity of programme personnel to adopt these approaches.

1. Self-help organizations of persons with disabilities and related associations

Persons with disabilities and their self-help organizations are recognized as the most equipped and best informed to speak on their behalf, who can contribute to solutions on issues that concern them. Advocacy is actively promoted by self-help groups of people with disabilities or their families, which have become a significant tool to promote self-advocacy, inclusion, equal opportunities and rights.

Self-help organizations should include marginalized persons with disabilities such as women and girls with disabilities, persons with intellectual disabilities. It is recommended that Governments, international funding agencies and non-governmental organizations establish policy to support and develop self-help organizations and that governments take steps to ensure to include self-help organizations in decision-making processes.

2. Women with disabilities

Women with disabilities are multiply disadvantaged through their status as women, as persons with disabilities, and the likelihood of living in poverty. It is recommended that governments ensure anti-discrimination measures, where appropriate, to protect women with disabilities; that self-help organizations adopt policies to promote full representation of women with disabilities; and that women with disabilities are included in the membership of national mainstream women's associations.

3. Early detection, early intervention and education

Less than 10% of children and youths with disabilities have access to any form of education compared with an enrolment rate of over 70% for non-disabled children and youths in primary education in the Asian and Pacific region. This exclusion from education of children and youths with disabilities results in exclusion from opportunity for further personal, social and vocational development.

It is recommended that governments ensure the detection of childhood disabilities at a very early age and that all infants and young children have access to community-based early intervention services. Another key target is that children with disabilities will be an integral part of the population targeted by the Millennium Development Goal Target 3, which is to ensure that, by 2015, children everywhere, boys and girls alike, will be able to complete a full course of primary schooling.

4. Poverty alleviation through social security and livelihood programmes

Persons with disabilities are the poorest of the poor. It is estimated that 160 million persons with disabilities (over 40% of the total) are living in poverty, unable to benefit from their socio-economic rights. Poverty and disability are mutually reinforcing as persons with disabilities are socially excluded and adequate social services are not provided.

It is recommended that governments should halve the proportion of persons with disabilities whose income/ consumption is less than one dollar a day. It is recommended that Governments to integrate disability dimensions into Millennium Development Goals baseline data collection and analysis, and to allocate a certain percentage of the total rural development / poverty alleviation funds towards persons with disabilities. ■

Leprosy and Social Exclusion

In India, there are several types of discrimination on the grounds of caste, religion, language, gender, class and tribe. In such a situation a question arises as to what kind of social change strategies would be initiated for integration of treated Leprosy patients and eradication of stigma? Social exclusion is another development related term through which the experience of the leprosy affected people is sometimes translated.

In India, the stigma and historical connections associated with leprosy are very strong and deep. Hence, Leprosy has been described as a neglected tropical disease and social killer because it causes disability, has economic implication and results in social exclusion compared with other diseases like malaria. The most widely accepted definition and description of stigma referring to bodily signs designed to expose something unusual or bad about the moral status of the signifier. Stigma itself is a complex issue, with the capacity to affect all facets of a leprosy-affected person's life.

Srikanth M.V and Aparajita Mishra, Leprosy and Social Exclusion: A Study among the Leprosy Patients in Sanjay Gandhi Nagar, MoulaAli in City of Hyderabad, Andhra Pradesh. Academia, April 2013

7

Antiquated Acts on Leprosy Amendments proposed and Action Taken Report (ATR)

Shri M. Venkaiah Naidu
Chairman, Committee on Petitions,
Rajya Sabha Secretariat, New Delhi

1. Indian Railways Act 1989

Recommendations to the Ministry

Ministry of Railways - amend Section 56 of Indian Railways Act, 1989, which gives power to railway authorities to refuse to carry persons suffering from leprosy.

ATR by the concerned Ministry

Leprosy does not appear in the list of infectious or contagious disease as mentioned in section 133(A) of Indian Railways Act, 1989.

There were no restrictions on Leprosy affected persons to travel in trains along with regular passengers since 1989.

Hence no amendment is required in the Act. Moreover, it has been decided by the Railways that the word “Leprosy” will be replaced by “Leprosy Affected Persons” and that the word “Leper” will not be used in the Railways’ parlance or premises.

2. Maharashtra State Road Transport Corporation Act 1980

Recommendations to the Ministry

Maharashtra Road Transport Corporation (MSRTC) – Provide concession to all leprosy patients including in the buses run by Brihan Mumbai Electricity Supply and Transport (BEST).

ATR by the concerned Ministry

Requested the Govt. of Maharashtra for modification of the Maharashtra State Road Transport Corporation (MSRTC) Act 1980 to cover all leprosy patients for concessional travel in the buses run by MSRTC.

Requested Brihan Mumbai Electricity Supply and Transport (BEST) to provide 75% concession to LAPs travelling in the buses run by BEST on the line of similar facility available in the buses run by MSRTC.

Source: *Rajya Sabha, committee on petitions, Hundred and Thirty-Eighth report, November, 2010*

3. Bombay Prevention of Begging Act, 1959

Recommendations to the Ministry

Greater Mumbai Corporation, Mumbai, Maharashtra. Delete the whole section 8(3) of the Bombay Prevention of Begging Act, 1959 that permits the court to order detention of persons wholly dependent on begging.

Detaining a person indefinitely because he is incurably helpless is also violation of human rights.

ATR by the concerned Ministry

Requested Govt. of Maharashtra to consider the amendment to the Bombay Beggary Prevention Act, 1959 by inserting a new sentence viz. “The section is not applicable to patients of leprosy whether cured or not”, in view of the fact that Leprosy is no more a dangerous disease, curable and leprosy affected persons (cured or not) should be integrated into the society. However, the Government of Maharashtra is yet to furnish any response regarding amendment of the said Act.

4. Persons with Disabilities (Equal opportunities, protection of rights and full participation) Act 1995.

Recommendations to the Ministry

Ministry of Social Justice & Empowerment - Waiver of 40% disability in the case of LAPs as stipulated under Section 2(t) of PWD Act,1995 in view of the fact that social prejudices due to visible deformities make the LAPs disabled to get gainful employment even if he is medically cured.

ATR by the concerned Ministry

PWD Act, 1995 does not recognize diseases but disabilities due to disease. Accordingly ‘leprosy cured persons’ are covered under the definition of disability under Section 2 (i) of the PWD Act and they are given the benefits as provided to persons with disability. In accordance of Section 2 (t) of the PWD Act,1995 the persons with disability means persons suffering from not less than 40% of any disability as certified by a medical authority.

There are so many other diseases, which, if included in the PWD Act would dilute the very purpose of framing a separate Act for the persons with disabilities. Further, any condition to waive the minimum disability percentage of 40% would open a plethora of requests from various other disabilities and would be difficult to accede to. Furthermore, bringing down 40 % disability criteria benchmark for LAPs may raise similar demands from all other categories of differently-abled persons.

5. Industrial Disputes Act 1947

Recommendations to the Ministry

Ministry of Labour & Employment - provide safeguard to LAPs workmen from termination/retrenchment by the management as provision of section 2 of

Industrial Disputes.

Act, 1947 has the element of subjective interpretation in the hand of appointing authority.

ATR by the concerned Ministry

Any workman discriminated against, on grounds of his being affected with leprosy or discharged from service, an industrial dispute can be raised under Section 2A of the Industrial Disputes Act, 1947 for the processes of conciliation and adjudication.

However, a permanent protection of jobs by delinking the requirements of jobs from the ability to discharge tasks, duties and responsibilities associated with them is not desirable and cannot be attempted through amendments to Industrial Disputes Act, 1947.

6. *Bombay Municipal Corporation Act 1888*

Recommendations to the Ministry

Bombay Municipal Corporation – Amend section 421 of the Bombay Municipal Corporation Act, 1888 that requires information to be given about existence of dangerous disease of unknown origin to the Health Officer for prevention of spread of the disease.

This provision is resorted to in respect of the person affected by leprosy whether he is cured or not.

ATR by the concerned Ministry

Requested Govt. of Maharashtra to consider the amendment by inserting a new sentence viz. “The section is not applicable to patients of leprosy whether cured or not”, at the end of Section 421 of the Bombay Municipal Corporation Act, 1888in view of the fact that Leprosy is no more a dangerous disease, curable and leprosy affected persons (cured or not) should be integrated into the society.

However, the Government of Maharashtra is yet to furnish any response regarding amendment of the said Act.

7. *Juvenile Justice and Care and Protection Act 2000*

Recommendations to the Ministry

Ministry of Women & Child Development - amend Section 48(2) of the JuvenileJustice (Care and Protection of Children) Act, 2000 which requires segregation of leprosy affected juvenile/ child for specialised treatment thereby subjecting him/her to discrimination in that Juvenile Home.

ATR by the concerned Ministry

Section 48 of the Juvenile Justice (Care and Protection of Children) Act, 2000, does not mention that leprosy as a disease is communicable and an inherently risky one. It is specifically mentioned in the said Section that where a juvenile/child is found to be suffering from leprosy, he shall be dealt with separately through specialized referral service or under the relevant law. Hence, there is no need for amendment in Section 48 under the JJ Act. However the words ‘leprosy’ and ‘leper asylum’ were proposed to be deleted from Sections 48 and 58 of the said Act in consultation with the Ministry of Law and Justice.

8. Motor Vehicles Act 1988

Recommendations to the Ministry

Ministry of Road Transport and Highways - amend Section 8(4) of the Motor Vehicles Act, 1988 which states that if the applicant is suffering from any disease or disability the licensing authority shall refuse to issue the learner’s license as the licensing authority uses his own judgment to refuse license to the LAPs.

ATR by the concerned Ministry

Person who was affected by leprosy per se could not be denied driving license under the Motor Vehicles Act, 1988 unless that person was physically incapacitated to drive a motor vehicle.

The RTO could not deny driving license unless the disease was self-revealed by the applicant or by medical examination done by the licensing authority. Written advisories have been sent to all State Govt./ UTs to issue instructions to all RTOs/ Licensing authorities not to discriminate LAPs while issuing learner’s license or regular driving license.

9. Rehabilitation Council of India Act 1992

Recommendations to the Ministry

Ministry of Social Justice & Empowerment - Amendment to other clauses of Section 2 (c) of the RCI Act 1992 to reflect the terminology of “leprosy affected persons” in the place of “leprosy cured person”.

ATR by the concerned Ministry

Substitution of the words “leprosy cured” by the words “leprosy affected persons” in Section 2 (c) may not be possible as there was no illustrative definition for the “leprosy affected persons”.

Disability should be long term physical, mental, intellectual or sensory impairment. RCI Act was not an instrument for overcoming disabilities and the social disability was something which belonged to a different domain and there were laws like Protection of Civil Rights Act, 1955 etc., which dealt with curbing untouchability or discrimination.

The issues raised and suggestions made have been noted and would be considered at the time the Rehabilitation Council of India Act, 1992 are amended. ■

8

Eliminating Discrimination Against Persons Affected by Leprosy - A proposed Bill

Justice Ajit Prakash Shah
Chairman,
Law Commission of India, Government of India,
New Delhi - 110 001

Introduction

On a reference from the then Minister for Law and Justice, the Law Commission of India undertook the task of identifying laws which can either be repealed or which need amendments in view of the existing climate of economic liberalization. The Commission also recognized the need for the modification and repeal of existing laws, regulations, policies, customs and practices that negatively affect Persons Affected by Leprosy (PALs) and promote their exclusion, segregation and discrimination.

In light of these observations, the Law Commission has undertaken the present study on "**Eliminating Discrimination against PALs**" in order to provide the Government with a detailed insight into the level of discrimination and stigma associated with Leprosy, along with its constructive recommendations for a new model law to eliminate discrimination faced by PALs.

To address precisely this concern, after a series of meetings and deliberations, the Law Commission of India has finalized its **Report No.256** and submitted for consideration by the Government on 7 April 2015.

The Law Commission of India believes that the fact that India is home to the most number of PALs in the world is a matter of deep shame. Further, despite clear scientific evidence and pioneering social efforts, the stigma associated with leprosy still continues unabated.

The proposed Bill is an important step in eliminating the social discrimination faced by such persons, a necessary precursor to their reintegration into society. As a humane society that believes in human rights for all, especially its poorest, the Law Commission believes that the Bill should be converted into a law as expeditiously as possible by the Government of India.

Source: *Law Commission of India, Report No.256, D.O.No.6(3)/273/2015-LC(LS) dated 7 April 2015*

ELIMINATING DISCRIMINATION AGAINST PALS (EDPAL) BILL, 2015

A Bill

to enact a comprehensive protection regime for PALs and members of their family; to eliminate any discrimination or denial of equal treatment; to repeal and amend existing laws that negatively affect such persons and promote their segregation and discrimination; and to enable the State to discharge its positive obligations through affirmative action

Reaffirming that all human beings are born free and equal in dignity and rights, and that everyone is entitled to the enjoyment of human rights without distinction of any kind, such as caste, sex, language, religion, disability or deformity, national or social origin, birth or other status;

Reaffirming that PALs and members of their family are entitled to be treated as individuals with dignity and bearers of human rights, including equality before the law and the equal protection of the law, without any discrimination;

Recalling India's obligations as a signatory to the United Nations Resolution on the Elimination of Discrimination against PALs and their Family Members, 2011, the United Nations Principles and Guidelines for the Elimination of Discrimination against PALs and their Family Members, 2010, and the United Nations Convention on the Rights of Persons with Disabilities 2006;

Enabling the government to give due consideration to the principles and guidelines mentioned herein, while repealing certain obsolete and archaic laws and formulating policies and guidelines for the equal and non-discriminatory treatment of PALs;

Now therefore be it enacted in the Sixty-fifth year of the Republic of India:-

CHAPTER I : PRELIMINARY

1. Commencement

(1) This Act may be called the Elimination of Discrimination against PALs Act, 2015.

(2) It extends to the whole of India.

(3) It shall come into force on such date as the Central Government may, by notification in the Official Gazette, appoint.

2. Definitions

In this Act, unless the context otherwise requires,

(1) "appropriate government" means,—

(i) in relation to the Central Government or any establishment wholly or substantially financed by that Government, or anybody constituted by a law made by Parliament or a

Cantonment Board constituted under the Cantonments Act, 2006, the Central Government; or

(ii) in relation to the State Government or any other establishment under sub-section (2) of this section that is not covered under clause (i) of this sub-section, the State Government;

(2) "establishment"– means and includes a company, club, firm or any other body corporate or association of persons jointly carrying out a systematic activity for consideration or otherwise including but not limited to;

(i) a society registered under the Societies Registration Act, 1860, or a co-operative society under the Co-operative Societies Act, 1912

(ii) a trust under the Indian Trusts Act, 1882 or corresponding state law under which trusts may be established;

(iii) any organization or institution or authority established by or under a Central Act or State Act or otherwise;

(iv) any industry under Section 2(j) of the Industrial Disputes Act, 1947; or

(v) any shop or establishment governed by a State Act concerning such shops and establishments;

(3) "disability due to Leprosy" – means grade 1 or grade 2 disability in the hand, leg or eye that hinders full and effective participation of a person affected by Leprosy in society equally with others, whether or not his extent of disability has been specified in measurable terms;

Explanation:

(i) Grade 1 disability includes sensory impairment, scars with sensory impairment or muscle weakness without contractures.

(ii) Grade 2 disability includes visible impairment, Lagophthalmos, Iridocyclitis, visual acuity of <6/60, burns, deep cracks, wounds (both simple and deep ulcers), muscle atrophy, bone absorption of shortening or contractures.

(4) "Leprosy" – means a disease triggered by Mycobacterium Leprae characterised by symptoms of pale and reddish skin, numbness of hands or feet or loss of feeling in a patch of skin, and which may lead to disability as defined under sub-section (3) of this section;

(5) "leprosy cured person" – includes, notwithstanding anything in the Persons with Disability Act, 1995 or any other law pertaining to persons with disability, any person affected by

Leprosy, regardless of the percentage of his disability, who has been certified by a registered medical practitioner, as having been administered with the first dose under Multi-Drug Therapy, which renders his illness non-contagious, and such person continues with or has completed treatment for Leprosy.

(6) “person affected by Leprosy” – means and includes a person who suffers from, or has previously suffered or has been cured of Leprosy, whether or not such person has undergone treatment under Multi-Drug Therapy;

(7) “Multi-Drug Therapy” (MDT) – means the medical treatment wherein a combination of drugs are administered to a person affected by Leprosy in order to render the infection non-contagious through the first dose and kill Mycobacterium Leprae;

(8) “members of their family”, with reference to PALs, means —

(i) spouse of the person affected by Leprosy;

(ii) parents of the person affected by Leprosy;

(iii)children of the person affected by leprosy; and

(iv) brothers or sisters of the person affected by Leprosy.

CHAPTER II : EQUALITY AND NON-DISCRIMINATION

3. Equality and non-discrimination

(1) No person, establishment or government, shall discriminate against any person affected by Leprosy, or members of his family on any ground in relation to their affliction with Leprosy, or their disability, physical attributes or any other form of their association with Leprosy;

(2) All PALs and members of their family shall be entitled to the recognition, enjoyment and exercise, on an equal basis, of all human rights including freedoms guaranteed by the Constitution of India.

4. Repeal of certain enactments

The statutes and provisions enumerated in Schedule I are hereby repealed.

5. Amendments to certain enactments

The statutes and provisions enumerated in column I of Schedule II shall stand amended in accordance with respective entries in column II of Schedule II.

6. Certain laws to be invalid

Laws that are not enumerated in Schedule I or Schedule II, whether Central or State, which directly or indirectly discriminate against PALs shall be invalid insofar as such laws discriminate against PALs.

Illustration: A, a person affected by Leprosy who is found begging, is arrested and detained under the provisions of a State Prevention of Begging Act, solely on account of his affliction with Leprosy. With the coming into force of this section, any such provision for the arrest and detention of PALs under the State Prevention of Begging Act shall be invalid. The detention and arrest of A will be invalid.

7. Substitution of certain terms

Notwithstanding any other law for the time being in force, in all laws that are in force, and in all official records of the Government of India, State Governments, and establishments defined under sub-section (2) of Section 2, the term 'leper' and other such terms in national, regional and local languages, shall be substituted by the term 'PALs' or any other term in the national, regional or local language that is synonymous.

CHAPTER III : RIGHTS OF PALS

8. Duty to uphold rights

(1) No government, establishment or person, shall deny PALs and members of their family, any rights guaranteed to them under this Chapter.

(2) All legislative, administrative and other measures necessary to ensure compliance of the provisions of this Chapter shall be undertaken by the appropriate government.

9. Right to health and treatment

(1) No person affected by Leprosy shall be denied the right to treatment for Leprosy under Multi-Drug Therapy.

(2) All PALs shall have the right to access other healthcare facilities including but not limited to reconstruction surgeries and medicines.

10. Disclosure of medical records - The medical records relating to Leprosy of PALs and members of their family shall be treated as confidential and shall not be disclosed to any person or establishment unless:
(1) the prior informed consent of the affected person to such disclosure has been obtained; or
(2) such disclosure, without such consent, is authorized by law.

11. Right to ownership of property - No person affected by Leprosy, or members of his family, shall be denied the right to own property or to reside, purchase, rent, use or otherwise occupy, any property, merely for reason of such person being affected by leprosy.

12. **Right to access public goods and services -** No person affected by Leprosy, or any member of his family, shall be denied the right to access, or enjoy or use any goods, accommodation, service, facility, benefit, privilege or opportunity dedicated for the use of the general public or customarily available to the public, whether or not for a specific fee, including shops, public restaurants, hotels and places of public entertainment or the use of wells, tanks, bathing ghats, roads, burial grounds or funeral ceremonies and places of public resort.

13. **Right to movement -** No person affected by Leprosy, or any member of his family, shall be denied the right to movement in respect of all or any public transport or for obtaining a driving license for all or any vehicle, on account of being affected with leprosy.

14. **Right to education -** No person affected by Leprosy, or any member of his family, shall be denied the right to education and training opportunities in any institution, including the right to continue or resume his education or training in any institution, after duly furnishing a certificate by a registered Medical Practitioner that attests that such affected person has been administered with the first dose under Multi-Drug Therapy and continues to undergo or has completed treatment for Leprosy or any such similar treatment as approved by the Government of India or World Health Organization.

15. **RIGHT TO EMPLOYMENT -** No person affected by Leprosy, or any member of his family, shall be denied the right to be nominated, selected or elected, or to continue his appointment, as the case may be, to a public office or for private employment, after he has duly furnished a certificate by a registered Medical Practitioner that attests that such person has been administered with the first dose under Multi-Drug Therapy and continues to undergo or has completed treatment for Leprosy.

16. **Right to form family -** No person affected by Leprosy, or any member of his family, shall be denied the right to marry, and form a family including through access to adoption or assisted procreation (including donor insemination).

CHAPTER IV : MEASURES FOR AFFIRMATIVE ACTION

17. **Duty to undertake measures -** Without prejudice to the generality of the obligations mentioned under Section 8 and in addition to them, the

appropriate government shall undertake all measures specified in this Chapter.

18. Health-related measures - The appropriate government shall undertake the following measures relating to healthcare, for all persons affected by Leprosy and members of their family, that shall include but not be limited to:

(1) implementation of awareness programmes for all persons affected by Leprosy that emphasise the importance of an early treatment through Multi-Drug Therapy, to reduce chances of any kind of disability as a result of Leprosy;

(2) formulation of guidelines and protocols for addressing the healthcare needs of all persons affected by Leprosy;

(3) access to healthcare facilities that include reconstruction surgeries, and goods and services for all persons affected by Leprosy, to improve the health status of, and respond to the needs of all persons affected by Leprosy;

(4) humane treatment of all persons affected by Leprosy by health care providers;

(5) adoption of policies, and programmes for education and training of healthcare professionals, to enable them to deliver the highest attainable standard of healthcare to all persons affected by Leprosy and members of their family;

(6) protection of all persons affected by Leprosy and members of their family against unethical or involuntary medical procedures or research, including in relation to vaccines, treatments or microbicides for terminal or such other diseases; and

(7) providing medical and psychological treatment and counselling for all persons affected by Leprosy and members of their family, to assist them in overcoming their trauma suffered on account of their disability, physical attributes or any other form of their association with Leprosy.

19. Measures related to ownership and title -

(1). The appropriate government shall make efforts to provide security of tenure, title and ownership of property for all persons affected by Leprosy and members of their family living in leprosy colonies.

(2) No person affected by Leprosy or members of his family shall be removed or evicted from the existing leprosy colonies without prior sanction of Central or State Commission of Leprosy, as the case may be, and without being rehabilitated and adequately compensated.

20. Measures related to social welfare - The appropriate government shall undertake the following measures relating to social welfare, for all persons affected by Leprosy, and members of their family, that shall include but not be limited to:

(1) formulation of special financial packages that are designed for providing means of livelihood and adequate housing for persons affected by Leprosy and their family members, during and after the treatment;

(2) formation and establishment of a Community-based Rehabilitation forum;

(3) promotion of schemes for neighbourhood support and security;

(4) access to social security and other social protection measures, including employment benefits, parental leave, unemployment benefits, health insurance or other social insurance, family benefits, funeral benefits, pensions and benefits with regard to the loss of support for spouses or partners as the result of illness or death on account of Leprosy, and poverty reduction strategies and programmes; and

(5) enforcement of social programmes, including support programmes, to address factors relating to discrimination of the affected persons, that increase their vulnerability to isolation, homelessness and mental trauma.

21. Measures related to education and employment - The appropriate government shall undertake the following measures relating to education and employment for PALs, who have either been cured of Leprosy, or who have been duly certified, by a registered Medical Practitioner, as having been administered with the first dose under Multi-Drug Therapy and is continuing treatment for Leprosy, and members of the family of any person affected by Leprosy, that shall include but not be limited to:

(1) implementation of educational programmes that impart education and training that is directed at the development of personalities, talents, and mental and physical abilities of persons, to their fullest potential, and responds to their needs; and

(2) access to employment and advancement opportunities, in all areas of public service, including all levels of government service and employment in public institutions.

22. Other measures - The appropriate government shall undertake the following other measures in the interest of all PALs and members of their family, that shall include but not be limited to:

(1) enforcement of social awareness programmes to dispel misconceptions surrounding Leprosy and disseminate information in respect of its treatment through Multi-Drug Therapy;

(2) enforcement of special programmes for addressing discrimination, prejudice and other social factors that undermine the health of PALs because of their disability, physical attributes; and

(3) implementation of training and awareness-raising programmes in all establishments and institutions, including but not limited to schools and hospitals, to raise awareness regarding the needs of those affected by or associated with the disease.

23. Participation in the formulation of policies - PALs shall be entitled to participate in the formulation of policies affecting their welfare.

24. Administration

(1) The Central Government shall within 12 months of the coming into force of this Act, by notification, constitute a Central Commission on Leprosy, to monitor the compliance of the provisions under Chapter III and Chapter IV of this Act in respect of all establishments for which the Central Government is the appropriate Government, and to make recommendations to the Central Government, for the proper implementation of this Act.

(2) State Governments shall, within 12 months of the coming into force of this Act, by notification, constitute a State Commission on Leprosy, to monitor the compliance of the provisions under Chapter III and Chapter IV of this Act in all establishments for which the State Government is the appropriate Government, and to make recommendations to the State Government, for the proper implementation of this Act within 12 months of the coming into force of this Act.

CHAPTER V : ENFORCEMENT AND REMEDIES

25. Non-compliance of provisions, rules or measures under the act - Notwithstanding any other law for the time being in force, any person affected by Leprosy or member of his family or a person acting bonafide on their behalf, aggrieved with the violation or non-compliance of the provisions of Part III of this Act or any rules made there under, may institute a petition against the concerned persons or establishments in the District Court in whose jurisdiction the said person ordinarily resides or where the violation or non-compliance is alleged to have taken place and the provisions of the Code of Civil Procedure, 1908, shall apply to such proceedings.

26. Legal aid

(1) Where persons aggrieved under Section 25 of this Act, are unable to, or do not have the sufficient means to, engage a legal practitioner to represent them in any proceeding under this Act, the appropriate Legal Services Authority under the Legal Services Authorities Act, 1987 shall provide legal aid to such persons.

(2) PALs and members of their family filing a petition under Section 25 of this Act shall be deemed to be persons entitled to legal services under Section 12 of the Legal Services Authorities Act, 1987.

27. Liability for non-compliance - In any petition under Section 25, where the Court finds that any person or establishment has breached or not complied with the provisions of this Act, it shall award to the person affected by Leprosy or a member of his family, compensation, and damages of not less than twenty five thousand rupees along with all costs incurred in litigation. ■

Six steps to tackle stigma in leprosy

The 2010 UN General Assembly called for governments to repeal discriminatory laws with the adoption of a resolution on the elimination of discrimination against persons affected by leprosy. By World Leprosy Day 2016, they could all be repealed if the following six steps were taken:

1. **Communities:** Groups of women and men affected by leprosy are supported to organize and negotiate for their rights.
2. **States:** Existing discriminatory laws on leprosy are reviewed and abolished.
3. **Media:** Stop using offensive words such as “leper” and take up cases of people affected by discriminatory laws.
4. **Human rights groups:** Advocate for the implementation of the 2010 U.N. General Assembly resolution on the elimination of discrimination against persons affected by leprosy.
5. **The United Nations:** If the U.N. sustainable development goals are to “leave no one behind,” then their impact on key vulnerable groups, including people affected by leprosy, must be measured.
6. **Donors:** Fund programs to tackle the social, as well as the medical, consequences of leprosy.

Marie Staunton. 6 ways to tackle stigma on leprosy, Inside Development, Global Views, World Leprosy Day, 26 January 2015.

9

The Rights of Persons with Disabilities (RPD) Bill, 2014

Legislative Brief
PRS Legislative Research, Institute for Policy Research Studies, New Delhi,

Context

According to the Census of India, 2011 disabled persons accounted for 2.21% of India's population. Of these, 20.3% have a movement-related (loco-motor) disability, 18.9% are those with hearing disabilities and 18.8% with vision-related disabilities. Currently, the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) (PWD) Act, 1995 specifies seven conditions as disabilities and makes special provisions for disabled persons including **'leprosy cured persons'** with regard to their rehabilitation, and opportunities for employment and education.

In 2007, India became a signatory to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The UNCRPD requires signatory states to make appropriate changes in law and policy to give effect to rights of disabled persons. Apart from the PWD Act, other laws that govern various aspects of disabilities include the Mental Health Act, 1987, the National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999 and the Rehabilitation Council of India Act, 1992.

In 2010, the **Ministry of Social Justice and Empowerment** constituted an expert committee under Dr. Sudha Kaul to draft a new Bill for persons with disabilities. The committee submitted a Draft Bill in 2011 that proposed to replace the PWD Act and addressed rights and entitlements for disabled persons.

Subsequently on February 7, 2014 the Rights of Persons with Disabilities Bill, 2014 was introduced in Rajya Sabha and referred to the Standing Committee on Social Justice and Empowerment on September 16, 2014. The Committee is scheduled to submit its report during the Budget Session 2015 (Status of Bill as on 30th September 2015 is 'pending').

Source: *The Rights of Persons with Disabilities (RPD) Bill, 2014, May 2015.*

Key Features

- The Bill replaces the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995.
- The Bill includes the following 19 conditions under disability: autism spectrum disorder; low vision; blindness; cerebral palsy; deaf blindness; hemophilia; hearing impairment; **leprosy cured person**; intellectual disability; mental illness; loco-motor disability; muscular dystrophy; multiple sclerosis; specific learning disabilities; speech and language disability; sickle cell disease; thalassemia; chronic neurological conditions and multiple disability. The Bill allows the central government to notify any other condition as a disability.
- Persons with "benchmark disabilities" are defined as those certified to have at least 40 per cent of the disabilities specified above.

Rights of persons with disabilities

- Persons with disabilities shall not be discriminated on grounds of their disability unless it is shown that the specific act is appropriate to achieve a legitimate aim. Persons with disabilities shall have the right to equality, personal liberty and to live in a community. They will not be obliged to live in any specific arrangement and shall have access to residential services and community support.
- The Election Commission (centre and state) has to ensure that polling stations and all electoral materials are accessible to persons with disabilities. Central and state governments have to ensure that all public documents are in accessible formats.
- The Disaster Management Authority (centre and state) will take necessary steps to include disabled persons in its disaster management activities for their safety and protection.

Special provisions for persons with benchmark disabilities

- **Education:** Children between the ages of six to 18 years, with a benchmark disability, have the right to free education in a neighborhood school or special school if required. All government and government aided institutions of higher education are required to reserve at least five per cent of seats for persons with benchmark disabilities. For admission in higher education institutions, they will be allowed relaxation in the upper age limit, by five years.
- **Employment:** Five per cent of government owned or controlled establishments shall be reserved for persons with benchmark disabilities. One per cent of this must be reserved for persons with (i) blindness and low

vision; (ii) hearing and speech impairment; (iii) loco-motor disability; (iv) autism, intellectual disability and mental illness; (v) multiple disabilities. The government may exempt any establishment from this provision. The central, state and local governments shall provide incentives to the private sector to ensure that at least five per cent of their work force is composed of persons with benchmark disability. Five per cent reservation to be provided for persons with benchmark disabilities in (i) allotment of agricultural land and housing in all relevant schemes and programmes; (ii) poverty alleviation schemes (with priority to women with benchmark disabilities); and (iii) allotment of land on concessional rate for purposes of business, enterprise, etc.

Authorities established under the Bill

- **National and State Commissions for persons with disabilities:** The central government shall constitute a National Commission, and state governments shall constitute a State Commission each, for disabled persons. The Commissions will be required to: (i) identify any laws, policies or programmes that are inconsistent with the Act; (ii) inquire into matters relating to deprivation of rights and safeguards available to disabled persons and recommend appropriate remedial measures; (iii) monitor implementation of the Act and utilization of funds disbursed by governments for the benefit of disabled persons, etc.

- **Central and State Advisory Boards on disability:** The central government shall constitute a Central Advisory Board, and state governments shall constitute a State Advisory Board each, for disability matters. State governments shall also constitute District-Level Committees. The functions of these advisory boards will include: (i) advising the government on policies and programmes with respect to disability; (ii) developing a national / state policy concerning persons with disabilities; (iii) recommending steps to ensure accessibility, reasonable accommodation, non-discrimination, etc.

Offences and penalties

- Any person, who violates provisions of the Act, or any rule or regulation made under it, shall be punishable with imprisonment up to six months and / or a fine of Rs. 10,000, or both. For any subsequent violation, imprisonment of up to two years and / or a fine of Rs.50,000 (Fifty thousands) to Rs.5,00,000 (Five lakhs) can be awarded.

- Whoever intentionally insults or intimidates a person with disability, or sexually exploits a woman or child with disability, shall be punishable with imprisonment between six months to five years and fine. ■

10

The position in International law could not be clearer: no discrimination

Tim Huges
Deputy Executive Director,
International Bar Association (IBA),
London, United Kingdom

Leprosy and the Law

India carries a special responsibility because it is the country with the most new cases of leprosy and the most laws discriminating against those with the disease. The Law Commission rightly observes that the laws in India on this issue are a matter of shame.

Its report is a model in setting out how to change the law, not merely to remove the old discrimination but to compel the state to provide those affected by leprosy with the social, economic and practical support which they need to help overcome the difficulties they face. Many other countries could learn much and achieve much by following the lead given by this remarkable report. I believe it should be circulated widely. It has been so clearly inspired by the 2010 U.N. resolution and accompanying principles and guidelines. It shows the road by which international law can travel to become new and better law at national level, although we still have much campaigning to do to make that happen in India.

We should continue to use these two documents, the principles and guidelines, and the India Law Commission report, to encourage lawyers and lawmakers everywhere to work until such new laws are introduced in all the countries where leprosy still diminishes lives in so unjust a way.

The IBA will carry on working with the international community to keep heightening its awareness of this ongoing injustice, and to keep international law extending and deepening its focus and agenda-setting on this issue of leprosy and to treat those things with proper and urgent priority.

The IBA will continue to urge and encourage lawyers and their national bar associations to work with leprosy-related NGOs to bring cases to court. As well as challenging old laws that are wrong, we want to see them removed and replaced by laws that guarantee all the rights guaranteed by international law. ■

Source: *Presentation at International Symposium on Leprosy and Human Rights, Geneva, June 18, 2015*

11

A critical analysis of various legislations and policies on disability in India

Dr. Hemalata
Deputy Director
National Centre for Disability Studies, IGNOU,
New Delhi - 110068

Policies on Disability in India

In India we have moved from charity to welfare and finally to rights based approach for persons with disabilities. We have also moved from the medical model of disability to social model which emphasizes that the society has to change in order to mainstream the persons with disability and provide them equal opportunities.

In essence, this perspective on disability means viewing people with disabilities as subjects and not as objects. It entails moving away from viewing people with disabilities as problems towards viewing them as holders of rights.

Importantly, it means locating problems outside the persons with disabilities. The primary responsibility for ensuring respect for the rights of persons with disabilities rests with the government. Our government has taken various steps to provide equal opportunities to persons with disabilities by enacting several Acts and implementing various policies and schemes for the empowerment of persons with disabilities. Our constitution guarantees equal rights to each individual. Following are the overview of the PwD Act, 1995 and National Policy for PwD, 2006.

PwD ACT, 1995

The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995 (PwD Act) is the most important piece of legislation enacted by the Parliament in the history of disability movement in India. The Persons with Disabilities Act was passed in December 1995, and became enforceable on Wednesday, 7 February 1996.

The passing of this Act gave effect to the proclamation on the full participation and equality of people with disabilities in the Asian and Pacific Regions. The ESCAP

Source: *MIER Journal of Educational Studies, Trends and Practices, Vol. 1, No 2 (2011)*

(Economic and Social Commission for Asia and Pacific) declared the period 1993-2002 as the Asian and Pacific Decade of Disabled Persons. India, being a signatory to this proclamation, started the process for drafting and enacting a specific legislation that ensures equal opportunities and full participation and protects the rights of persons with disabilities.

The drafting of the PwD Act was primarily led by persons with disabilities themselves with support from many like-minded professionals spanning both government and non-government organizations.

The Act puts the responsibility on society to provide equal opportunities to persons with disabilities for their full participation in everyday life. It prohibits discrimination on the ground of disability in every sphere of life and strives to create a society where persons with disability lead a life of equality and dignity.

The main objectives of the Persons with Disabilities Act are summarized as below:

a) To ensure that the government takes responsibility for prevention of disabilities, protection of the rights of persons with disabilities, provision of medical care, education, training, employment and rehabilitation of persons with disabilities.

b) To create a barrier- free environment for persons with disabilities.

c) To remove any discrimination against persons with disabilities in the sharing of development benefits.

d) To protect persons with disabilities against abuses and exploitation.

e) To lay down strategies that will ensure comprehensive programmes and services and equal opportunities for persons with disabilities.

f) To make special provisions for including persons with disabilities in mainstream society.

g) To establish Co-ordination Committees and Executive Committees at the Central and State levels in order to ensure the full implementation of the provisions under the Act.

The PwD Act recognises the following seven disabilities:

1. Blindness,
2. Low vision,
3. Leprosy – cured,
4. Hearing impairment,
5. Locomotor Disability,
6. Mental retardation and
7. Mental Illness

NATIONAL POLICY FOR PERSONS WITH DISABILITIES, 2006

The National Policy for Persons with Disabilities was released in February 2006. The policy was developed in response to the need to have a comprehensive document that will inform all our decisions and actions in relation to provisions for persons with disabilities.

The National Policy recognizes that persons with disabilities are valuable human resource for the country and seeks to create an environment that provides them equal opportunities, protection of their rights and full participation in society.

The policy is committed to ensure that persons with disabilities exercise their rights through a range of equal opportunities provided through provisions in early identification and support, education, rehabilitation programmes, employment, social security, barrier-free environment, trained human resources, recreation and cultural options, and access to appropriate aids and appliances.

The policy emphasizes that children will receive education right from preschool years to primary education, secondary, post secondary and vocational training. Children will receive this education through a continuum of educational options ranging from regular schools, community based rehabilitation programmes to home-based programmes for children with severe disabilities, who choose to receive education in this mode.

Education is to be always provided by trained and qualified persons. The policy makes a special mention of protecting the rights of young children with disabilities to access care, protection and security. It also highlights the need to ensure that children with all levels of ability are included in accessing education, recreation, rehabilitation, health and other specialized services.

Women with disabilities get a special recognition in this policy. The policy focuses on supporting programmes which will provide education, employment and rehabilitation, developed for the unique needs of women with disabilities. The policy also highlights the need to protect women with disabilities against abuse and exploitation.

The Ministry of Social Justice and Empowerment is the nodal agency to implement the provisions included in the National Policy. The Ministry coordinates the implementation of the policy in collaboration with many agencies including other related government agencies, disabled people’s organizations, NGOs working in the area of disability, representatives of family or parent associations and experts and professionals.

■

12

Where does Indian disability Law stand in the present International scenario?

Saurabh Jain,
National Law Institute University,
Bhopal, Madhya Pradesh

It is now recognized that the disabled deserve a dignified status in society on the same terms as the non-disabled. Disabled people are a vast minority group, which has been subjected to direct and indirect discrimination for centuries in most countries of the world, including India.

The human rights movement has boldly and categorically shifted the attention of policy-makers from the mere provision of charitable services to vigorously protecting their basic right to dignity and self-respect. In the new scenario, the disabled are viewed as individuals with a wide range of abilities and each one of them willing and capable of utilizing his/her potential and talents.

Society, on the other hand, is seen as the real cause of the misery of people with disabilities since it continues to put numerous barriers as expressed in education, employment, architecture, transport, health and other activities.

Critical analysis of the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995

Disabilities are conventionally defined in medical science on a three-point scale established by the World Health Organisation in 1980 ranging from impairments, disabilities and handicaps.

The World Health Organisation (WHO), in its International Classification of Impairments, Disabilities and Handicaps, (ICIDH) makes a distinction between impairment, disability and handicap. These three concepts are defined by it as follows:

(a) Impairment is "any loss or abnormality of psychological, physiological or anatomical structure or function". Impairments are disturbances at the level of the organs, which includes defects in or loss of a limb, organ or other body structure, as well as defects in or loss of a mental function.

Source: *http://www.ebc-india.com/lawyer/articles/847.htm accessed on 20 September 2015*

(b) Disability is a "restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being". It describes a functional limitation or activity restriction caused by impairment.

(c) A handicap is a "disadvantage for a given individual, resulting from an impairment or disability that limits or prevents the fulfillment of a role that is normal (depending on age, sex and social and cultural factors) for that individual". The term is also a classification of "circumstances in which disabled people are likely to find themselves".

However, it seems that the definition under Section 2 (i) of the Act does not recognize the international classification given by the World Health Organization. It also seems that the Act has tried to cover every kind of disability under Section 2 (i), but in fact the term disability is included in a very narrow sense in the Act. The definition, in fact, has left some of the important categories, which are included in the term disability world over.

According to conservative estimates, approximately 6% of India's population is disabled. And if we go by what the UN officials or various other experts say, the figure could very well be in double digits. In certain countries, even diabetics are given shade under the umbrella of disability. Such countries and societies are now looking at disability as a social issue and not as a medical one, as is the case in India where disability is a stigma. To be disabled means to be a person without a leg or arm or eye or twisted or worse, crooked! People are ashamed to be labeled "disabled".

Problems in implementation

Even after the enactment of the Indian Act, the aims and purposes with which the Act was enacted are not served. The reasons are some lacunas in the Indian Act, as well as lack of implementation. And, these are the reasons why India is lagging behind in the international arena.

It is worthwhile to mention some of them here that hinder the process to provide for education, employment, affirmative action, full participation, non-discrimination, and manpower development of People with Disabilities (PWD).

Section 44 of the PWD Act provides for the special measures to be taken by the establishments in the transport sector, within the limits of their economic capacity and development for the benefit of persons with disabilities.

In India authorities concerned are yet to take measures to ensure the implementation of the provision for "accessibility". The authorities are taking undue advantage of the term "within the limits of their economic capacity". They have been using this term as a defence to negate the right granted by the statute. To ensure strict implementation of the provision it is necessary that a deadline must be fixed for the authorities to comply with the provisions of the PWD Act.

Under the PWD Act the Chief Commissioner and Commissioners for Persons with Disabilities are envisaged to be the watchdog bodies with the powers of a civil court. However, very few facilities have been provided to these offices and they thus remain ineffective.

In conclusion, it could be said that some lacunas and problems in its implementation makes Indian disability law lag behind in the international scenario. It is ironical to note that every time it takes a court notice for the authorities to start the implementation of the provisions of any legislation. And, it is only to the extent of initiating the process of constituting different committees.

As far as the actual working of these committees goes, probably it would require another notice of the court of law. The Hon'ble Supreme Court in this case, has expressed its hope and trust that the respective committees will discharge their obligations under the Act so as to achieve the objectives for which the Act has been enacted. ■

GLOBAL APPEAL 2014

To end stigma and discrimination against people affected by leprosy Endorsed by National Human Rights Institutions

In December 2010, recognizing the disease's devastating social, economic and psychological impact, the U.N. General Assembly adopted a resolution on elimination of discrimination against persons affected by leprosy and their family members. -The resolution is accompanied by principles and guidelines and reaffirms that people affected by leprosy and their family members should be treated as individuals with dignity and are entitled to all human rights and fundamental freedoms under customary international law, relevant conventions and national constitutions and laws.

As national human rights institutions, we applaud the U.N. resolution and condemn all leprosy-related human rights violations. We uphold the right of people affected by leprosy to live in dignity, free from discrimination. We pledge our support to help to bring down the remaining barriers of stigma and prejudice that stand in their way.

Launched in Jakarta, Indonesia, on January 27, 2014. Global Appeal 2014 is an initiative of Yohei Sasakawa, WHO Goodwill Ambassador for Leprosy Elimination and Chairman of The Nippon Foundation.

13

Protect and Promote the Human Rights of People Affected by Leprosy

National Human Rights Commission
Government of India,
New Delhi - 110 023

Despite the fact that leprosy is easily curable, the stigma and discrimination faced by the people, affected by leprosy, continues to be a serious problem. The National Human Rights Commission (NHRC) has been concerned about the protection and promotion of human rights of people affected with leprosy.

The United Nations General Assembly unanimously adopted a Resolution on **"Elimination of Discrimination Against PALs and Their Family Members"** in 2010. It called upon governments to abolish discriminatory legislation and remove discriminatory language from official publications~ provide quality health care to PALs and promote their social inclusion.

Keeping in view its concerted efforts to protect and promote the human rights of people affected with leprosy, the NHRC organized a one day National Conference on Leprosy and gave many important suggestions / recommendations to the Center, States and UTs authorities, following the discussions with the participants during the National Conferences on Leprosy. The participants include officials / representatives of Central / State Governments and Union Territory Administrations, National Commissions, State Human Rights Commissions, other State Commissions, health experts and health scientists, legal experts, representatives of technical organizations, international organizations, non-governmental organizations and civil society.

National Conference on Leprosy – 18 September 2012

In order to discuss the issues the commission organized a one day National Conference on Leprosy on 18th September 2012 at New Delhi. Many important suggestions / recommendations emanated out of this National Conference and these were forwarded to all State Governments

---

Source : http://www.disabledpeoplesinternational.org accessed on 15.09.2015 and Union Territory Administrations for compliance.

Important suggestions / recommendations

- There is a need to give wide circulation to the principles and guidelines prepared by the Human Rights Council of United Nations and which emphanise that person affected by leprosy and their familties members should be treated as individuals with dignity.
- State Governments must take steps to eradicate discrimination being faced by PALs by developing appropriate IEC material and ensure its wider dissemination.
- There is a need to generate awareness on the issue of leprosy by way of organizing training programmes, workshop, lectures, nukkad nataks, TV spots, radio talks, puppetry, etc for all sections of the society.
- The discrimintory provisions in central and state laws affecting Civil and Political Rights and Ecconomic, Social and Cultural Rights may either be replealed or suitably ammended. Research study would be carried out to suggest suitable changes.
- Leprsoy affected persons should be given proper care and tratment in all hospitals without discrimination.
- In order to provide an enabling envoirnment for leprosy affected persons and their families, there should not be separate colonies for leprsoy affected persons. Efforts must be made to settle them in the mainstream society by allocating lands and housing. They should live in sporadic manner in the society.
- The State Governments must take steps to improve living conditions in the colonies where people affected by leprosy reside.
- Leprosy should be included in the school sylabus so that children are senitive towards lerpsoy affected / cured persons and their families.
- The Central Government must ensure inclusion of PALs in the poverty alleviation schemes.
- There is a need to provide adequate and reasonable level of pension to PALs keeping the best practice followed by Government of Delhi as a model.
- There is a need to review criteria of minimum requirement of 40% disability under the PWD Act (1995) for persons affected by lerpsoy to obtain disability certificate. Most of the leprsoy affected persons are having 40% disability and hence are not elegible for disability certificate.
- Employment in Government can be provided as is done in Karnataka where

130 Group D employees have been recruited. In Kerala, they are employed as hospital attendants. Such practices can be replicated.

- Steps must be taken to ensure easy availability of disability certificate to PALs by organizing special camps.
- The State Governments must take steps to motivate the persons affected by leprsoy in developing self help groups for selfcare like dressing of their ulcers.
- Leprsoy affected and cured persons and their families should live a dignified life. For this, they need to be empowered with basic human rights like ‘right to education’, ‘right to work’, ‘right to health’, ‘right to food’, ‘right to housing’ and other economic, social and cultural rights. They should have access to all these rights without facing any kind of discrimination.
- There are no leprosy specific schemes and these should be designed. There is no scheme for allotment of land to them. Further reservation within persons with disabilities is required as they are most vulnerable with little say.
- There is a need for early detaction and ASHAs may be provided incentive across the country as is being done in some states like Karnataka. This State also has Swarna Arogya Chatanya Programme for early detection, which may be implemented elsewhere.

National Conference on Leprosy – 17 April 2015

A one-day National Conference on leprosy was organized by the National Human Rights Commission at New Delhi on 17 April 2015 with the objective to follow-up the suggestions / recommendations of the National Conference on leprosy held on 18 September 2012 and to address the issues of concerns related to leprosy and suggest appropriate strategies to deal with them. Based on the deliberations held in three plenary sessions, the following recommendations were made:

Major recommendations:

1. There is a need for vigorous dissemination of recommendations of the National Conference organized by NHRC earlier on the issue of leprosy on 18 September 2012 for proper implementation by all concerned authorities. SHRCs involvement in implementation of recommendations of both National Conferences (2012 and 2015) is a must, then only implementation is possible.
2. The detailed recommendations made by the Committee on Petitions of Rajya Sabha in its 131st Report should be followed up for implementation. The Action Taken Report of the Governments covered in the 138th Report of the Committee of Petition indicates a large number of recommendations have still not been

completely implemented. Hence, there is a need to take up these recommendations for logical conclusion especially those relating to social and economic discrimination of leprosy affected persons and their families.

3. There is a need to suitably address the issue of disability certificate to leprosy affected persons by evolving a separate set of criteria even when they do not fulfill the minimum 40% disability. The Department for Empowerment of Persons with Disabilities should revisit the guidelines issued on the subject in 2001 and also hold special camps for leprosy affected persons for distribution of disability certificate to them. There is a need to explore a sub-quota of reservations in jobs for leprosy affected persons. In aggregate 5% reservation may be provided for in the pending Bill for Persons with Disabilities.

4. In order to empower children of leprosy affected persons, there is a need to provide free school education and free higher education to them. The children of leprosy affected parents need utmost help for their proper education. If the second generation is uplifted through education and employment, the poverty circle of the family would be broken and their quality of life will improve.

5. The Ministry of Social Justice and Empowerment have educational promotion scheme for persons with disabilities. These schemes need to be extended to children of PALs with disabilities in view of the stigma and discrimination they face.

6. Centre and State Governments should elicit the support of the corporate sector in adopting leper colonies for rehabilitation and empowerment of the leprosy affected persons and their families under their corporate social responsibility. ■

14

Deendayal Disabled Rehabilitation Scheme to promote Voluntary Action for Persons with Disabilities (Revised)

Dr. Arbind Prasad
Joint Secretary, Disability Development Bureau, Ministry of Social Justice & Empowerment, New Delhi

Section 2 (w) of the PwD Act, 1995, defines "rehabilitation" as "a process aimed at enabling persons with disabilities to reach and maintain their optimal, physical, sensory, intellectual, psychiatric or social functional levels". Some of the main components of rehabilitation are:

i. provision of assistive aids and appliances
ii. education
iii. vocational training
iv. assistance for employment
v. training or assistance for independent living

The Central Government has been providing grant-in-aid to non-governmental organizations over successive Five Year Plans through various schemes for projects relating to rehabilitation of persons with disabilities. To facilitate delivery of various services to persons with disabilities by voluntary organizations, the Ministry of Social Justice and Empowerment is administering DDRS scheme and providing grants-in-aid to NGOs for the following projects that are useful for the people with disabilities including those affected by leprosy:-

i. Vocational Training Centres. These projects are meant for persons with disabilities in the age group of 15-35 years and are expected to provide skills to enable such persons to move towards economic independence.

ii. Project for Rehabilitation of Leprosy Cured Persons (LCPs) The basic aim of this project is to empower leprosy cured persons with skills to enable them to improve their socio-economic condition. The projects can include vocational training units and homes (only for severely disabled).

iii. Project relating to Survey, Identification, Awareness and Sensitization. The objectives include identification of disability to facilitate

---

Source: *http://socialjustice.nic.in/ddrsmain.php accessed on 25 September 2015* early intervention through awareness creation, sensitization of parents/ guardians on management needs of persons with disabilities, suggesting appropriate rehabilitation programmes and facilitation of research on trends relating to various disabilities.

iv. Project for Community Based Rehabilitation. The objective of this project is to rehabilitate and train disabled individuals and integrate them into their communities. The focus is on partnership between the disabled persons, families, community and health professionals to provide needed services in a non-institutional setting, in an environment where services for disabled persons are seriously limited or absent. These projects are particularly relevant in rural areas.

v. Seminars / Workshops / Rural Camps. This project is to support seminars/ workshops/ rural camps with specified objectives, outcomes and tangible outputs.

The maximum level of support could be up to 90% of the eligible amount of grant for the project.

The following organizations/institutions shall be eligible for assistance under this scheme:

i. Organizations registered under the Societies Registration Act, 1860 (XXI of 1860), or any relevant Act of the State/Union Territory; or,

ii. A public trust registered under the law for the time being in force; or,

iii. A charitable company licensed under section 25 of the Companies Act, 1958,

Further, the registration should have been in force for at least 2 years at the time of applying for grant under this scheme.

Note: *In exceptional cases, Secretary, Ministry of Social Justice & Empowerment is empowered to waive the condition of minimum time period, for reasons to be recorded in writing, based on detailed justification.*

An organization/institution specified in Para 3.4.1(i) to (iii) should have the following characteristics:

i. It should have a properly constituted managing body with its powers, duties and responsibilities clearly defined and laid down in writing.

ii. It should have resources, facilities and experience for undertaking the programme.

iii. It should not be run for profit to any individual or a body of individuals.

iv. It should not discriminate against any person or group of persons on the grounds of sex, religion, caste or creed.

v. It should ordinarily have existed for a period of two years.

vi. Its financial position should be sound.

Note: The conditions related to experience, period of existence and financial soundness may be relaxed by the Secretary in consultation with Financial Advisor, in rare and exceptional cases, for reasons to be recorded in writing.

Grants-in-aid for new projects will be sanctioned keeping in view the recommendations of the State Government/State Commissioners / National Institutions/Organisations/any other system designated by the Ministry of Social Justice & Empowerment for this purpose on the form prescribed.

Application Form for Grant-In-Aid to Voluntary Organisations Working in the Field of Disabilities can be downloaded from http://socialjustice.nic.in/pdf/newapplicationform-ddrs.pdf ■

Right to health: from concept to action

The rights approach, while useful in its own sphere, must be complemented and supported by analysis of the wide range of conditions and structures which shape the fulfillment or denial of rights. Such a contextualized approach to health rights may have some of the following features:

- It would be based on a vision of collective health rights, emphasizing the rights of communities and hence should strongly promote community mobilization.
- It would be informed by a critical understanding of the health sector crisis, including the underlying political economy of the impact of neoliberal policies, weakening of public health systems, privatization and their impact on health services.
- It would not hesitate to identify and challenge the social and political barriers that block the fulfillment of health rights.
- It would combine demands for the Right to Health Care and the Right to Health determinants as part of a holistic approach.
- It would facilitate alliances of the health movement with other social movements.

Claudio Schuftan & Laura Turiano,
Coordinators, Right to Health campaign,
People Health Movement, New Delhi

15

Integration and empowerment of leprosy affected persons Response from the Government

Shri. Bhagat Singh Koshyari
Chairman, Committee on Petitions,
Rajya Sabha Secretariat, New Delhi - 110 001

After conclusion of oral evidence of the officers of concerned Ministries / Departments, the Committee on Petitions present this report on the action taken by Government on the observations / recommendations contained in its Hundred and Thirty-first Report (131st) to the Council. The report has been prepared taking into account the submissions made by the Secretaries of the concerned Ministries / Departments and the progress report submitted to it. 7. The Committee considered and adopted the draft Hundred and Thirty-eighth (138th) Report in its meeting held on 15th November, 2010. The following are the Recommendation, Action Taken Report (ATR) and the Outlook presented.

WAIVER OF 40% DISABILITY IN THE CASE OF LAPs

Recommendation: Waiver of 40% disability in the case of LAPs as stipulated under Section 2(t) of PWD Act,1995 in view of the fact that social prejudices due to visible deformities make the LAPs disabled to get gainful employment even if he is medically cured.

ATR: The Ministry of Social Justice & Empowerment informed that 'leprosy cured persons' are covered under the definition of disability under Section 2(i) of the PWD Act. They are given the benefits as provided to persons with disability in the PWD Act, 1995. In accordance of Section 2(t) of the PWD Act,1995 the persons with disability means persons suffering from not less than 40% of any disability as certified by a medical authority. There are so many other diseases, which, if included in the PWD Act would dilute the very purpose of framing a separate Act for the persons with disabilities. Further, any condition to waive the minimum disability percentage of 40% would open a plethora of requests from various other disabilities and would be difficult to accede to. Furthermore, bringing down 40 percent disability criteria

---

Source: *138th Report, Committee on Petitions, Rajya Sabha Secretariat, New Delhi, 15 November, 2010* benchmark for LAPs may raise similar demands from all other categories of differently-abled persons.

Outlook: The Committee had reiterates its earlier recommendation for giving disability certificate to the LAPs having less than 40% of disabilities with the sole purpose of making their economic and social integration into the society effective.

UNIFORM SUSTENANCE ALLOWANCE OF LAPS

Recommendation: The Ministry of Social Justice & Empowerment to give allowance @Rs.2000/-per month to LAPs, who are not able to earn their livelihood, uniformly in all the States/UTs for maintenance. The maintenance allowance could be shared on 50:50 ratios between the Central and State Governments.

ATR: The Ministry of Social Justice & Empowerment informed that in pursuance of Section 68 of Persons with Disability Act, 1995, some states/UTs are giving unemployment allowance to persons with disabilities. However, their rates and other parameters vary considerably. In addition to unemployment allowance, some states are giving disability pension also. National policy for Persons with Disabilities, under the heading social protection, provides that for providing adequate social security to persons with disabilities. The scope of the Indira Gandhi National Pension Scheme, under Ministry of Rural Development, had been expanded to include persons with disabilities in the age group of 18 to 64 years, below the poverty line but the benefit of that scheme may be availed by persons having more than 80% disability (severe disability) or multiple disability (more than one disability). States Governments and UT administrations will be encouraged to rationalize the amount of pension and unemployment allowance.

Outlook: The Committee stresses upon the fact that sustenance allowance to the LAPs is the responsibility of the Ministry of Social Justice and Empowerment and since it does not involve huge expenditure, the Ministry should look into the matter on humanitarian ground.

PUBLIC AWARENESS CAMPAIGN

Recommendation: The Ministry of Health & Family Welfare in coordination with the Ministry of Information and Broadcasting and Publicity Departments of the State Governments, should launch a nation-wide campaign advocating the curability of leprosy and the humanitarian aspect of leprosy affected persons, so that people appreciate their problems and come forward with a helping hand to their cause. The Film Divisions of M of I&B was also urged to prepare documentaries for the dissemination of positive messages across the masses.

ATR: The Ministry of Health and Family Welfare mentioned that under the programme, Information Education and Communication (IEC) activities, which are being carried out by the States, Mass media, Outdoor media, Folk media and Inter Personal Communication (IPC) are being used to communicate key messages about the disease across the country. IEC under National Leprosy Eradication Programme (NLEP) is decentralized to the States/UTs, who make their own plan and implement the same. The IEC activities are now carried out under the National Rural Health Mission (NRHM) to make it more effective at lower cost. The Ministry of Information & Broadcasting was requested to prepare documentaries for the dissemination of positive messages about leprosy across the masses. Further, funds have been provided to States for carrying out IEC activities as per their approved annual action plans which include posters, banners, leaflets, handbills and brochures; wall paintings and hoardings, rallies and school quiz; interpersonal communication workshop at block level for Government officials, teachers, NGOs, PRIs, ASHAs/ Anganwadi workers; folk shows; phone in programme. Besides, School Health Programmes, Health Melas at PHC/CHC, Village Health and Nutrition days have been organized under National Rural Health Mission for dissemination of leprosy Messages.

Outlook: The committee recommended that the advocacy programmes through both print and electronic media would continue to create the necessary awareness about positive aspects of leprosy.

MCR FOOTWEAR FOR LAPs

Recommendation: The Ministry of Health & Family Welfare to make available of two pairs of MCR chappals to LAPs in a year.

ATR: The Ministry of Health & Family Welfare informed that the no. of footwear has been increased from 60 to 120 pairs / per district / per year under the Eleventh Five Year Plan. For this purpose, Govt. of India allocates funds on an average of 120 pairs of MCR footwear per year per District for supply to eligible LAPs. The budgetary support for providing two pair of MCR footwear to the LAPs in the country is Rs. 1.9 Crores per year and there was no budget constraint in regard to the provision of adequate number of MCR footwear to LAPs.

Outlook: The Committee expresses its satisfaction over the action taken by Ministry of Health and Family Welfare.

FREE MEDICAL FACILITIES TO LAP COLONIES

Recommendation: The Primary Health Centers (PHC) under the Ministry of Health & Family Welfare to be designated as nodal agencies to take care of the medical needs of LAPs residing in self-settled colonies. The medical officer of nearby PHC or Government hospital must visit the LAPs colony at least once a week to attend to medical requirements of LAPs. The Government should arrange free medicine to LAPs through its designated medical stores instead of depending only on international agencies and missionary services.

ATR: The Ministry of Health & Family Welfare has issued a letter to the State Health Secretaries for providing public health & medical services free of charge to LAPs living in self-settled colonies. The State/UTs have informed that Medical / Para-medical workers are visiting these colonies on regular basis (weekly/ fortnightly) for providing medical services to LAPs in colonies. The medicines required by LAPs are being provided free of cost. Monitoring of the medical services provided to leprosy colonies is being done at the district level by District Leprosy Officers by making field visits. The Chief Medical Officer also review medical services provided in colonies during monthly review meeting. In addition to field visits, the State Leprosy Officer also monitors the aforesaid activity during monthly review meetings. At the Central level monitoring of this activity is regularly being carried out during the quarterly meetings of States Leprosy Officers (SLOs).

Outlook: The Committee notes the extant monitoring system that ensures weekly visit of medical and para-medical officials to self-settled colonies of LAPs to cater to medical needs of LAPs.

ANTODAYA CARD TO THE FAMILIES OF LAPS STAYING IN SELFSETTLED COLONIES

Recommendation: The Ministry of Consumer Affairs, Food & Public Distribution to issue Antodaya Anna Yojana (AAY) Card to the families of the LAPs staying in self-settled colonies.

ATR: The Ministry of Consumer Affairs, Food & Public Distribution opined that this scheme is only a segment of the Below Poverty Line (BPL) households to be covered under Targeted Public Distribution System (TPDS) being implemented by that Department jointly with the State Govt. and UT Administrations. For identification of the poorest of the poor families in rural and urban areas to be covered under Antodaya Anna Yojana (AAY), elaborate guidelines were issued. As per these guidelines, Leprosy Affected Persons would be eligible for coverage under the scheme provided they are from identified BPL families and are terminally ill or disabled. However, income/asset base being the criteria for identification of BPL and AAY families it would not be possible to cover those Leprosy Affected Persons who are from APL/affluent families under AAY.

Outlook: The Committee noted that there were only a limited number of LAPs (50,197) residing in 612 self-settled colonies throughout the country. It opined that out of about 110 crore of the total population, this small number of LAPs residing in self-settled colonies, marginalized due to social stigma, should be considered for issuance of AAY/BPL Card from humanitarian angle and for that purpose the existing norms for identification of AAY/BPL beneficiary may be relaxed in the case of LAPs, for their rehabilitation.

CIVIC AMENITIES IN SELF SETTLED COLONIES

Recommendation: The Central Government to advise State Governments and local authorities to provide civic amenities in all self-settled colonies free of charge. Where no colonies have been identified, the LAPs should be given housing sites under the Indira Awas Yozana and electricity provided under the 'Rajiv Gandhi Grameen Vidyutikaran Yojana'.

ATR: The Ministry of Rural Development stated that Indira Awaas Yojana Scheme is being implemented in the rural areas of all States/UTs (except Delhi & Chandigarh). The objective of the scheme is to provide financial assistance for construction/ upgradation of houses to BPL rural households belonging to SCs/STs and freed bonded labourers and non-SC/ ST rural households, widows and physically handicapped persons living in the rural areas. At present, there is no scheme for providing house sites, though a proposal in this regard is under consideration. However, Leprosy Affected Persons (LAPs) belonging to BPL are also eligible for financial assistance under IAY in their turn". The Ministry had requested all States to pay special attention to LAPs for providing homestead sites while giving financial assistance to BPL, under Indira Awaas Yojana Scheme. The Ministry of Power informed that under Rajiv Gandhi Grameen Vidhyutikaran Yojana (RGGVY), free electricity service connections are provided to BPL families. In case LAPs belongs to BPL, they will get the free service connections. However, they have to pay the tariff as decided by the State Power Utility'.

Outlook: The Committee notes the advisory issued to State Governments by the Ministries of Rural Development and Power and desires that the LAPs should get special attention from State Governments in the allotment of site under Indira Awaas Yojana Scheme and power under Rajiv Kutir Jyoti Yojana. It hopes all the States/UTs would respond to the advisory in a positive way.

FREE EDUCATION TO THE CHILDREN OF LAPS

Recommendation: The Ministry of Human Resource Development to take up the matter with the State Governments and impress upon them to attend to the educational needs of the children of LAPs with the kind of compassion and urgency they deserve.

ATR: The Ministry of Human Resource Development responded that they would like to examine the feasibility of preparing a scheme for the dependents of LAPs which may take some time. Central Government Ministries / Departments may earmark funds for reimbursing the total cost of the higher education of few bright children of LAPs. These funds can be managed by apex bodies like UGC, AICTE, Medial Council of India and ICAR etc. Similar action can be taken by State Governments also. It is suggested that the fees of the dependents of LAPs who get admission in the centrally funded technical institutes could be reimbursed from a scheme which may be formulated in the Ministry of Health & Family Welfare who may act as Nodal Ministry. The Right of Children to Free and Compulsory to Education Act, 2009 contains a provision wherein the States will be required to bring all the dropout children of LAPs to school.

Outlook: The Committee is of the view that the Department of Higher Education may coordinate with the Ministry of Health & Family Welfare for sponsorship / scholarship to enhance access to higher education to the dependent wards of LAPs. ■

Factors contributing to stigma

In a systematic review of risk factors contributing to stigma, the basis of stigma development was found to be the visibility of the disfigurements and disability augmented by the stereotypes of the society, knowledge and the status of the person in terms of economy, education and ability to participate in society.

The level of perceived stigma score was higher in in-patients compared to those who attended OPD. The higher perceived stigma score was found in illiterate and those who had less than 5 years of education compared to those who had more than 5 years. The impact of education on perceived stigma score could be to increase the overall knowledge on disease and an increased ability to resist the negative stereotypes attached to the disease.

Similarly, economic inadequacy and the lower income group participants showed significantly higher perceived stigma compared to those who had higher income. Change in occupation in leprosy affected persons has been one of the grave consequences of disability caused by leprosy.

Bipin Adhikari, Nils Kaehler, Robert S. Chapman, Shristi Raut, Paul Roche. Factors Affecting Perceived Stigma in Leprosy Affected Persons in Western Nepal, PLOS Neglected Tropical Diseases, June 2014.

16

The Right to Health : Obligations of the State

Secretariat
Office of the High Commissioner for Human Rights & WHO Press, World Health Organization, Geneva Switzerland.

Core minimum obligation

The Committee on Economic, Social and Cultural Rights has also stressed that States have a *core minimum obligation* to ensure the satisfaction of minimum essential levels of each of the rights under the Covenant. While these essential levels are, to some extent, resource-dependent, they should be given priority by the State in its efforts to realize the rights under the Covenant. State obligations fall into three categories, namely the obligations to *respect, protect* and *fulfil.*

The obligation to respect

States to refrain from interfering directly or indirectly with the right to health and denying or limiting access to health-care services; from imposing discriminatory practices relating to women's health status and needs; from withholding, censoring or misrepresenting health information; and from infringing on the right to privacy.

The obligation to protect

States should adopt legislation or other measures to ensure that private actors conform with human rights standards when providing health care or other services; ensure that privatization does not constitute a threat to the availability, accessibility, acceptability and quality of health-care facilities, goods and services; protect individuals from acts that may be harmful to their right to health.

The obligation to fulfil

States to adopt appropriate legislative, administrative, budgetary, judicial, promotional and other measures to fully realize the right to health. States must, adopt a national health policy or a national health plan covering the public and private sectors; ensure that public health doctors and other medical staff are sufficient and properly trained; and provide information and counselling on health-related issues. ■

Source: *Fact Sheet 31, Office of the United Nations High Commissioner for Human Rights & World Health Organization, p 25 - 27*

Opinion of People Affected by Leprosy

Listening to the voices of people affected by leprosy, it is proposed that any new Post-2015 global development framework:

1. Ensures that poverty reduction goals promote equity and inclusion of those marginalized by disability and neglected tropical diseases such as leprosy.
2. Includes indicators that measure inclusion of the most marginalized in development, specifically including disability-related indicators and targets across all goals.
3. Ensures access to affordable, quality health care that is disability-friendly, accessible to the most marginalized and provides specialist leprosy services within an integrated system.
4. Improves preventative health care systems, so that health education, including that on disability, leprosy and other neglected tropical diseases, is given due priority.
5. Improves the quality and inclusiveness of education and training at all levels, ensuring places of learning are accessible to people with disabilities and are fully inclusive.
6. Increases employment opportunities that include disabled people, valuing their skills and the contribution they can make to the economy.
7. Improves infrastructure development (including roads, schools, hospitals and clinics) ensuring that construction is accessible to people with disabilities.
8. Improves food security for the poorest of the poor through improved access to affordable food but also through provision of safety net support, particularly for people with disabilities and the elderly.
9. Recognizes that housing, water and sanitation are basic rights and ensures that provisions are accessible to people with disabilities.
10. Ensures improved technology and communications reach rural areas and are used wherever possible to facilitate the inclusion of people with disabilities.

Sian Arulanantham,
'Addressing inequality and exclusion – the opinion of people affected by leprosy in Africa and Asia, as to what should be included in any post Millennium Development Goal framework'.
Lepr Rev (2014) 85, 133–140

Reduce leprosy cases to 'zero' !!

“The stigma attached to the disease and low levels of awareness in the community about it add to deterrence in early detection and treatment of leprosy, which is the only time-tested way to completely reduce leprosy cases to 'zero'.

Now that the number of leprosy cases has come down, we need to renew our commitment in order to completely eliminate this disease from the world.

Detection of leprosy in children is evidence of continued transmission of the disease in the community, while grade 2 disabilities indicate delayed detection of the disease. We now need to work towards zero child cases with visible deformity or grade 2 disabilities by 2020.

We also need to detect all new leprosy cases before disability. Focused case finding activities should be rolled out in these areas for early detection of cases and complete treatment with MDT; they still are the basic tenets of leprosy control. Breaking the chain of transmission between the patients and healthy population remains 'the strategic choice' for controlling leprosy.”

Poonam Khetrapal Singh, Regional Director, WHO - SEARO, New Delhi
'Eliminating Leprosy Needs Renewed Efforts, Greater Push'