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# Planning Leprosy Elimination in the Context of Rapid Case Detection Campaigns in India: Challenges and Issues in Policy Implementation

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**Abstract:** India's rapid leprosy case detection campaigns towards leprosy elimination was a massive health campaign towards leprosy control, targeting the detection of 'hidden cases' and 'interrupting the transmission'. However, a critical evaluation of the practices and the policies during the rapid leprosy case detection campaigns highlights significant gaps regarding policy implementation; a careful evaluation of such gaps provides important inputs for future healthcare programmes. The present paper critically evaluates selected aspects regarding the implementation of rapid leprosy case detection campaigns by considering first hand observations. The study finds that micro-planning during such rapid drives holds the key towards leprosy elimination. A regional and culture specific approach in programme implementation will bring successful results in implementing disease specific drives, especially like leprosy. Issues in socio-cultural stigma in leprosy hold significant bearings in anti-leprosy programmes. Addressing the underreporting of relapsed, deformity as well as the actual number of cases is an eminent challenge in leprosy elimination. Management of the treatment regimen of leprosy in rural and tribal areas, particularly among the patients with grade II deformities needs emphasis. Training the Field Level Workers (FLWs), sensitizing leprosy care personals regarding patients' perspectives are contemplative aspects for similar drives in future. Most importantly, a round the year surveillance with a focus on preventive measures is the need of the time. Along with, an inclusive leprosy care policy towards the rehabilitation and welfare of the patients than the simple cure needs to be prioritized.

***Key Words:*** NLEP, Health planning and Policy, Infectious Diseases, Leprosy; LCDC; Medical Anthropology

## INTRODUCTION

India adopted National Leprosy Elimination Program (NLEP) in the year 1993, when the nation was facing the big challenge of very high case load (prevalence rate (PR) about 14/10,000), to bring it to the elimination target (PR<1/10,000) by the year 2000; however the elimination level was achieved only 6 years later in the year 2005 (PR at 0.95/10,000). Elimination of leprosy as a public health problem (PR<1/10,000) in India is in itself a highly significant success and a great relief in the history of epidemiological intervention in any widespread and complex disease prevalence set up. The reporting of Pausibasilary (PB) cases has also decreased indicating increasing success in control of the disease. However, the success rate of such achievement in further reducing the prevalence of leprosy in post-elimination period, in last a decade, has not been significantly sustainable as there has been a very little change in case load during that period (supplementary figure 1). The annual case load is truly remaining huge while considered in number (than the PR rate) which is worrisome and a serious concern in country's healthcare system.

It is evident that India has still been contributing more than 50% caseload to the total leprosy burden worldwide for last several years [1]. The huge numbers of year wise patient load at a nearly consistent PR during these years are estimated to have another equal number of patients as hidden burden [2]. A joint report (2016) by Indian government health agencies and World Health Organization (WHO) has reported that the case detection capacity under the present leprosy care system is much below the intensity of occurrence of new cases, while the number of cases being detected is less than the actual number of occurrence [3]. The reemergence of the disease has been huge in post-elimination era[4] with increased number of fresh patients being added to the treatment regimen, in spite of the fact that efforts are continuously being made by targeting the 'hidden leprosy menace and to break the cycle of infection[5]'. Proactive steps such as Intensive Case Detection Drive (ICDD), Leprosy Case Detection Campaigns (LCDC) have been undertaken during the year 2015 and 2016 in the line of the objectives of the 12th Five Year Plan (ending in 2017) [6]. In this context, it is necessary to research and evaluate the existing data and trend in NLEP along with thoroughly examining the ground level realities and constraints hindering the output and successful implementation of leprosy care management. We believe that the paper carry valuable inputs in its findings for other disease control programs also.

## METHODS

The focus of the present paper is to evaluate the NLEP both from secondary data reports as well as from primary field findings, where by putting LCDC as a context, to highlight the emerging health issues and significant challenges in leprosy elimination; the issues in policy implementation towards leprosy care and management is the other major aspect. The present paper critically evaluates the persisting challenges in NLEP on the basis of the analysis of the data from 2010-11 onwards. The paper with limited first hand findings from the field along with a thorough observation of the implementation of LCDC program at the field level undertaken during the 2nd half of the year 2016 also tries to bring in the important emerging issues and their explanations.

The latest LCDC during September 2016 was conducted with a focus on leprosy endemic districts by targeting the 'hidden cases'[5] and 'interruption of the disease infection'[7]. We undertook a study by looking into various aspects of this case detection drive in selected areas of Odisha, a high leprosy endemic states in India. The study was approved by the Institutional Ethical Committee prior to the original research was undertaken. Written and verbal consents (as per the necessity) of the selected patients were taken before including them in the study.

The data collection, analysis and presentation in the present study have been made in two stages: first, the collection and analysis of the data from secondary data sources in the annual epidemiological status of the disease on the several selected aspects available with NLEP. We collected the annual report of NLEP available online on its site, starting from the year 2008-09 to the year 2015-16 and we analysed the data reported in these reports. However, considering the accessibility of the online data, we considered period 2010-11 year and onwards. Necessary comparisons on different selected aspects were made and the results were presented in tabular as well as graphical formats.

Secondly, we collected primary data from the field and investigated the various aspects of our several observations that we find in the report, for example, cause of increase in disability, consistent rate of prevalence, disease management, shortcomings in implementation of elimination strategy etc. Our investigation on selected aspects at primary data level is in a limited study set ups. We took the LCDC as a context in leprosy elimination in the process of our analysis.

The fieldwork for the present cross-sectional cohort study was conducted during the months of August through October 2016 in selected leprosy endemic areas in Odisha state; Odisha carries a historically high case load. Prior administrative cooperation from the government authority was sought and was obtained for the conduct of the field research. An active support and cooperation of the local administrative as well as medical authorities was highly encouraging during the field data collection. The field study was started one month prior to the commencement of the LCDC. A list of 30 selected villages was obtained. Similarly, the list of already existing patients both released from treatment (RFT) and under the treatment regimen of multi-drug therapy (MDT) was obtained from local authorities at (Primary Healthcare Centres) PHCs. Effort was made to reach maximum number of patients whose details were obtained from the PHC records. Additionally, details were collected regarding the past cured, relapsed and otherwise undocumented or lost patients on records. Houses of the patients with details in record were visited and data was collected at their places. Patients with fear of social stigmatization were interviewed at their own places and time of convenience. Necessary confidentiality was properly maintained where the patients so requested. Multiple visits to the houses of several patients were also made due to their non-availability at home or out of their time constraint. The list and contact number of village-wise accredited social health activists (ASHAs) and Angan-wadi workers(AWWs) was also obtained from appropriate authorities. Similarly, the block level leprosy supervisors for the selected villages were contacted and data on last five years on demographic status of leprosy was obtained. The training program for the block leprosy supervisors before the staring of LCDC was attended informally. The rapid case detection campaign during the selected time for the studied areas was observed at the field level. A structured questionnaire was used for the collection of the data at field level. A log book was maintained during the field research. The data and information collected from the cured and existing patients, local key informants, local health workers (ASHAs and AWWs) and leprosy supervisors were analyzed and the findings were summarized. Information specific to LCDC were selected and was collected during the field data collection.

## RESULTS

Table 1 represents the year wise distribution of the patients starting for 2010-11 period till present (as data available). It indicates the distribution (%) of the disease in various populations, women and disease type categories. The rate of prevalence of disease among schedule tribes (STs) and scheduled castes (SCs) during the period 2010-11 was observed to be 14.31% and 18.69% respectively which during the period 2015-16 was observed to be 18.79% and 18.57% respectively. The rate of prevalence of leprosy among the women was 36.2% during the period 2010-11 which was found to be 38.33% during the period 2015-16. The prevalence of child leprosy cases during the period 2010-11 being 9.83% has remained at 8.94% during the period 2015-16. The prevalence of PB and MB cases during the period 2010-11 was observed to be 51.42% and 48.58% which became 48.73% and51.27% during the period 2015-16.

**Table 1**
**Year wise prevalence rate distributions (%) of the patients in to various population, gender and diseases type categories**

| *Time Period* | *ST* | *SC* | *PB* | *MB* | *Child MB* | *Child PB* | *Child Total* | *Female cases* |
|---|---|---|---|---|---|---|---|---|
| 2010-11 | 14.31 | 18.69 | 51.42 | 48.58 | 3.04 | 6.79 | 9.83 | 36.20 |
| 2011-12 | 15.83 | 18.4 | 50.07 | 49.93 | 3.04 | 6.63 | 9.67 | 37.01 |
| 2012-13 | 17.01 | 18.49 | 50.08 | 49.92 | 3.17 | 6.77 | 9.93 | 37.72 |
| 2013-14 | 17.88 | 18.03 | 48.52 | 51.48 | 3.06 | 6.43 | 9.49 | 36.91 |
| 2014-15 | 17.88 | 18.00 | 47.18 | 52.82 | 2.97 | 6.06 | 9.04 | 36.87 |
| 2015-16 | 18.79 | 18.57 | 48.73 | 51.27 | 2.77 | 6.18 | 8.94 | 38.33 |

**Figure 1: Prevalence and the patterns of trends of leprosy cases among STs, SCs, Females and Children in India during the period of 2010-11 to 2015-16. (Source, NLEP India)**

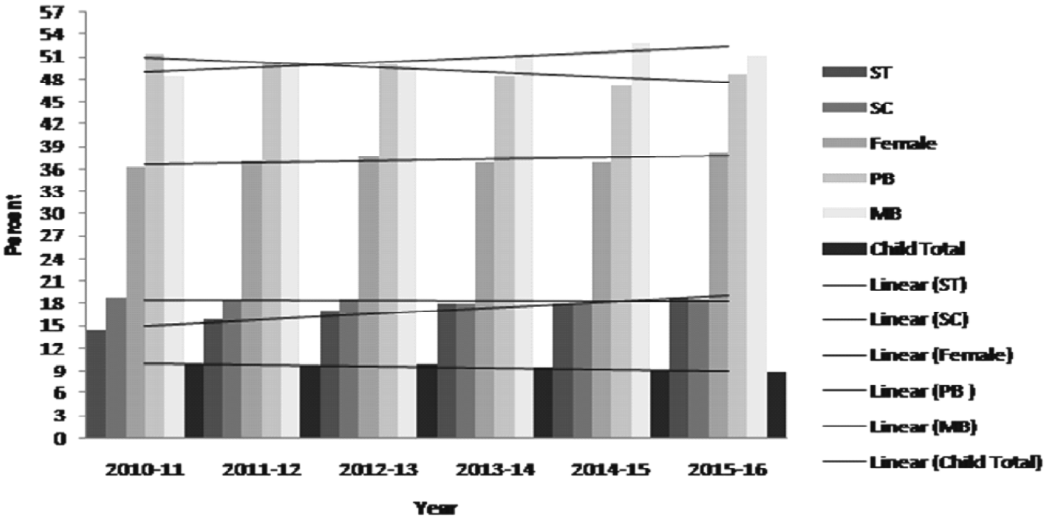


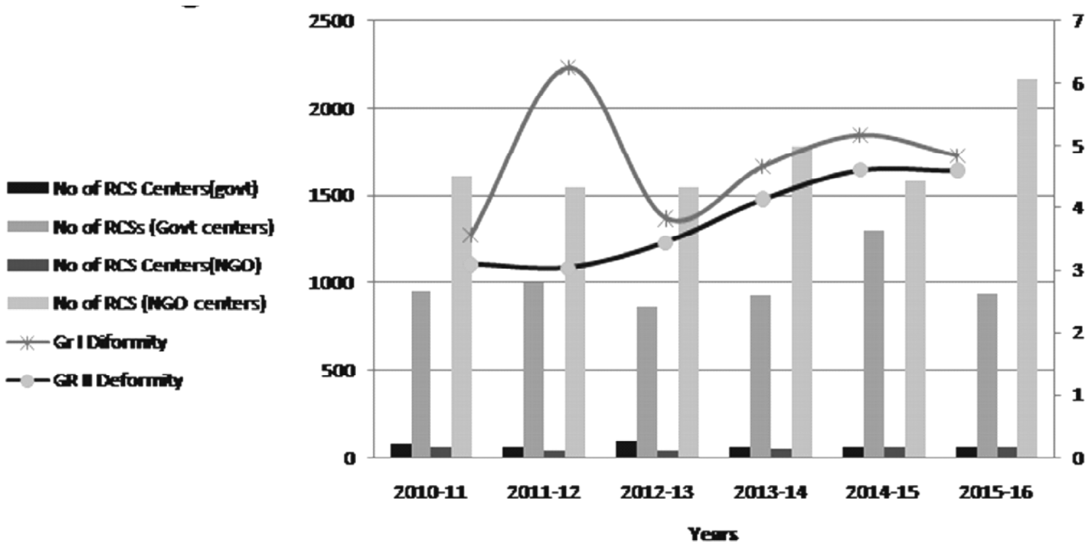
Figure 1 represents the trends of prevalence of leprosy among STs, SCs, Females and Children in India during 2010-11 to 2015-16. The figure also highlights the pattern of incidences of reported PB and MB cases during the same above period.

**Table 2**
**Year wise status of Disability (in %) and RCS support**

| *Time Period* | *Gr I Dis* | *GR II Dis* | *No of RCS Center(Govt)* | *No of RCS cases (Govt)* | *No of RCS Centers (NGO)* | *No of RCS cases (NGO)* |
|---|---|---|---|---|---|---|
| 2010-11 | 3.58 | 3.1 | 72 | 956 | 53 | 1614 |
| 2011-12 | 6.25 | 3.04 | 51 | 996 | 41 | 1552 |
| 2012-13 | 3.84 | 3.45 | 90 | 865 | 40 | 1548 |
| 2013-14 | 4.67 | 4.14 | 58 | 921 | 48 | 1786 |
| 2014-15 | 5.18 | 4.61 | 57 | 1297 | 52 | 1586 |
| 2015-16 | 4.85 | 4.6 | 58 | 934 | 54 | 2173 |
| Total | | | | 5969 | | 10259 |

Table 2 shows the year wise statuses of Grade I and II disabilities, numbers of government and NGO supported reconstructive surgery centers and the number of cases taken up by those centers. The figure shows that the grade I and Grade II disabilities at 3.58% and 3.1% respectively of the total cases during the period 2010-11 while this statistics was found to be 4.85% and 4.6% respectively in the latest available report in 2015-16. On the other hand 58 government administered RCH centers conducted 5969 RCSs during 2010-11 to 2015-16 while 54 NGO governed RCS centers took up 10259 cases during the same period.

**Figure 2: Number of RCS centers and number of RCS cases handled at government and non government agencies during 2010-11 to 2015-16 showing the trend of Grade I and Grade II deformities during that period**



*Note:* RCS center and RCS cases are in numbers with the scale on the left side. Trends of deformities are in percentages and are represented with scale on right side

Figure 2 represents the trends of RCS centers and RCS cases handled at government and NGO levels from the period of 2010-11 to the period of 2015-16. Similarly, the figure also shows the trends of prevalence rate in Grade I and II disability rates during the same period of time.

Table 3 shows the burden of disability in terms of Grade I and Grade II separately for each year period as well as in total till the year 2016. This burden has been calculated for the major 13 endemic states that carry the more than 95% burden of leprosy in India. The status of disability burden till the period 2010-11 was with 55385 numbers of Grade I and 125756 numbers of Grade II disability cases in the country. Furthermore, during the same time the 16 major states carried 54058 numbers (97.6%) of the total 55385 Grade I and 123109 numbers (97.9%) of the total 125756 numbers of Grade II disability burden. Similarly, the burden of total reported disability at national level till 2016 is 388691 with the 16 states

### Table 3
### Year-wise and total burden of disability (Grade I and II separately and grand total) at state and national level in 13 major endemic states and India

| *Major states* | *Disabi-lity* | | *Insen-sitive feet* | *Disabi-lity* | | *Insen-sitive feet* | *Disabi-lity* | | *Insen-sitive feet* | *Disabi-lity* | | *Insen-sitive feet* | *Disabi-lity* | | *Insen-sitive feet* | *Disabi-lity* | | *Insen-sitive feet* | *Disabi-lity* | | *Insen-sitive feet* |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | *Gr I* | *Gr II* | | *Gr I* | *Gr II* | | *Gr I* | *Gr II* | | *Gr I* | *Gr II* | | *Gr I* | *Gr II* | | *Gr I* | *Gr II* | | *Gr I* | *Gr II* | |
| | *Up to the year 2011* | | | *For year 2011-12* | | | *For year 2012-13* | | | *For year 2013-14* | | | *For year 2014-15* | | | *For year 2015-16* | | | *total till 2016* | | |
| AP | 7575 | 33897 | 4416 | 249 | 324 | 460 | 280 | 412 | 694 | 226 | 418 | 583 | 332 | 242 | 579 | 115 | 289 | 312 | 8777 | 35582 | 7044 |
| Assam | 343 | 566 | 405 | 78 | 72 | 68 | 114 | 76 | 68 | 93 | 80 | 114 | 87 | 115 | 105 | 84 | 80 | 85 | 799 | 989 | 845 |
| Bihar | 2712 | 7164 | 3872 | 296 | 334 | 698 | 357 | 510 | 667 | 305 | 513 | 514 | 297 | 525 | 505 | 373 | 583 | 723 | 4340 | 9629 | 6979 |
| Chhatisgarh | 656 | 874 | 887 | 356 | 378 | 913 | 421 | 464 | 1285 | 468 | 607 | 1708 | 486 | 694 | 1333 | 482 | 756 | 1682 | 2869 | 3773 | 7808 |
| Gujarat | 4643 | 8287 | 5978 | 3488 | 171 | 709 | 394 | 256 | 773 | 430 | 298 | 813 | 471 | 279 | 753 | 433 | 275 | 689 | 9859 | 9566 | 9715 |
| Jharkhand | 621 | 2429 | 881 | 77 | 55 | 457 | 114 | 52 | 511 | 138 | 88 | 525 | 188 | 124 | 467 | 129 | 102 | 412 | 1267 | 2850 | 3253 |
| Karnataka | 1744 | 2540 | 2282 | 325 | 125 | 383 | 242 | 113 | 273 | 252 | 129 | 274 | 306 | 146 | 321 | 182 | 104 | 254 | 3051 | 3157 | 3787 |
| MP | 9998 | 4991 | 9471 | 758 | 301 | 641 | 780 | 333 | 622 | 1049 | 317 | 549 | 1028 | 391 | 628 | 1016 | 483 | 721 | 14629 | 6816 | 12632 |
| Maharastra | 6321 | 14548 | 8560 | 264 | 331 | 2037 | 341 | 644 | 2026 | 736 | 813 | 1427 | 945 | 713 | 1640 | 793 | 397 | 1294 | 9400 | 17446 | 16984 |
| Odisha | 7254 | 14979 | 12324 | 373 | 254 | 2453 | 346 | 265 | 2092 | 499 | 449 | 2510 | 356 | 404 | 2167 | 563 | 593 | 2202 | 9391 | 16944 | 23748 |
| Rajastan | 535 | 305 | 397 | 246 | 45 | 72 | 273 | 45 | 61 | 208 | 40 | 65 | 134 | 57 | 86 | 101 | 67 | 79 | 1497 | 559 | 760 |
| Tamilnadu | 6122 | 12006 | 10747 | 198 | 168 | 161 | 153 | 172 | 219 | 149 | 164 | 183 | 202 | 187 | 460 | 214 | 219 | 317 | 7038 | 12916 | 12087 |
| Telengana | | | | | | | | | | | | 139 | 182 | 250 | 131 | 189 | 152 | 270 | 371 | 402 | |
| UP | 3890 | 12133 | 16023 | 540 | 671 | 1993 | 612 | 703 | 1803 | 711 | 722 | 1772 | 602 | 682 | 1821 | 670 | 887 | 1978 | 7025 | 15798 | 25390 |
| WB | 1644 | 8390 | 6456 | 355 | 379 | 1232 | 370 | 289 | 1052 | 273 | 234 | 1280 | 415 | 466 | 1694 | 374 | 377 | 1703 | 3431 | 10135 | 13417 |
| Delhi | | | 65 | 99 | 284 | 112 | 127 | 325 | 125 | 150 | 343 | 198 | 367 | 209 | 232 | 290 | 185 | 732 | 1033 | 1346 | |
| total 13 states | 54058 | 123109 | 82699 | 7668 | 3707 | 12561 | 4909 | 4461 | 12471 | 5662 | 5022 | 12660 | 6186 | 5574 | 13018 | 5892 | 5691 | 12788 | 84375 | 147564 | 146197 |
| National total | 55385 | 125756 | 85624 | 7957 | 3865 | 12761 | 5175 | 4650 | 12637 | 5932 | 5256 | 12901 | 6516 | 5794 | 13351 | 6180 | 5851 | 13100 | 87145 | 151172 | 150374 |
| | | | | | | | | | | | | | | | | | | | | 13 states | 378136 |
| | | | | | | | | | | | | | | | | | | | | Grand total | 388691 |

## Table 4
## Analysis of the status and involvement level of ASHAs in NLEP, their case reporting and treatment completion and received incentives

| *Major states* | *Total cases* | *No. of leprosy cases diagnosed out of referral by ASHA* | *No. of cases completed treatment with ASHA supervision* | *No of ASHA position* | *No of ASHAs Trained with NLEP* | *Total cases* | *No. of leprosy cases diagnosed out of referral by ASHA* | *No. of cases completed treatment with ASHA supervision* | *No. of ASHA Paid incentive* | *Total cases* | *No. of leprosy cases diagnosed out of referral by ASHA* | *No. of cases completed treatment with ASHA supervision* | *No. of ASHA Paid incentive* |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | *For the year 2011* | | | | | *For the year 2015* | | | | *For the year 2016* | | |
| AP | 5110 | 2142 | 1133 | 66537 | 60185 | 2753 | 1195 | 820 | 513 | 3129 | 1228 | 1341 | 3279 |
| Assam | 1239 | 138 | 78 | 3554 | 25 | | 118 | 176 | 156 | | 157 | 81 | 114 |
| Bihar | 11221 | 3363 | 2441 | 78983 | 28966 | 10100 | 5032 | 3812 | 1930 | 10328 | 5936 | 4707 | 3676 |
| Chhatisgarh | 5304 | 82 | 57 | 59113 | 34234 | 5700 | 0 | 0 | 0 | 5941 | 2091 | 788 | 350 |
| Gujarat | 5043 | 834 | 400 | 28633 | 25314 | 5282 | 1696 | 2374 | 2834 | 4850 | 1424 | 1827 | 1900 |
| Jharkhand | 3183 | 1247 | 655 | 40964 | 35000 | 2457 | 1658 | 874 | 538 | 3429 | 1502 | 1216 | 616 |
| Karnataka | 2995 | 444 | 194 | 32685 | 16044 | 2800 | 644 | 738 | 738 | 2726 | 607 | 572 | 429 |
| MP | 4589 | 1090 | 608 | 50113 | 35118 | 5399 | 1485 | 1251 | 0 | 5922 | 0 | 0 | 0 |
| Maharastra | 9984 | 3138 | 2256 | 59220 | 11625 | 10813 | 3456 | 4249 | 1278 | 11379 | 3333 | 1560 | 402 |
| Odisha | 3679 | 1430 | 1006 | 41102 | 15173 | 6405 | 3642 | 3832 | 3240 | 5423 | 5205 | 4530 | 5273 |
| Rajastan | 1346 | 53 | 11 | 43521 | 22276 | | 26 | 28 | 10 | | 25 | 30 | 3 |
| Tamilnadu | 3571 | 7 | 1 | 1329 | 917 | 2993 | 183 | 133 | 135 | 2888 | 73 | 70 | 119 |
| Telengana | | | | | | 2056 | 910 | 699 | 184 | 2045 | 803 | 841 | 223 |
| UP | 16484 | 5739 | 4171 | 132600 | 123340 | 14428 | 1976 | 1379 | 1172 | 14099 | 4106 | 2334 | 2235 |
| WB | 8944 | 756 | 312 | 36313 | 15337 | 8242 | 2724 | 2210 | 2972 | 9054 | 2694 | 2399 | 2038 |
| Delhi | 1330 | 1 | 1 | 2519 | 1707 | 1138 | 14 | 10 | 14 | 2240 | 3 | 52 | 16 |
| Total of major states | 84022 | 20464 | 13324 | 677186 | 425261 | 80566 | 24759 | 22585 | 15714 | 81408 | 29187 | 22348 | 20673 |
| Total | 87190 | 20616 | 13433 | 804512 | 501709* | 86147 | 25065 | 22891 | 16011 | 88833 | 29379 | 22753 | 20944 |

MP no of trained ASHAs on Govt record is 351188 which make the total number 817779 against 804512 sanctioned position. We presumed it as with an extra 8.

carrying 378136 number (97.3%) of disable cases. Similarly, there were 85624 numbers of cases with insensitive foot which has increased to 150374 by the 2016. Majority states of the endemic 16 states were observed with a consistently high trend of new disability rate, both among the overall and child cases which is a serious concern.

We tried to explore the involvement of ASHAs in NLEP and its outcome both at secondary data level as well as from primary field visit based villages' level. We also looked into the scope of improvement in their performance in increased case detection. With respect to secondary sources, data could be retrieves for only 2010-11, 2014-15 and 2015-16 periods from the NLEP annual reports. We did not consider the number of ASHAs trained during the period of 2014-15 and 2015-16 as no separate statistics is available on their training and the data was presented as combined with Anganwadi workers (AWWs). Table 4 represents the state wise number of ASHA workers (available only for the period of 2010-11) and the number of ASHAs trained under NLEP; the data shows out of total about 0.8 million ASHAs in India about 0.5 million were trend by 2010-11 under NLEP, though rest ASHAs might have received the training in later periods till the year 2016. We have calculated the total number of leprosy cases detected for the periods and the participation of ASHAs in referring these detected cases in the presented three periods. The table also represents the total number of ASHAs paid incentives for their participation in case detection and taking care of completion of the MDT by the patients. All these data were calculated for the 16 major states with high number of case detections as well as at overall level. However, these figures did not represent data and outcomes of the LCDC program.

## DISCUSSION

The annual case detection rate of new MB cases during past six years shows a little encouraging trend (Table 1) with almost consistent or increasing case detection rate (Figure 1), hence a limited progress in disease control. Furthermore, Considering the detection of the large number of leprosy patients consistently during last several years, India is long way behind its own set target for elimination[8]. New MB cases recorded at 45% in the 2006-07, in the immediate year following the declaration of leprosy elimination, have sharply increased to 51.27% during the year 2015-16 [8]. An increase in the MB cases along with a fall in overall as well as PB case loads is considered a positive trend towards achieving the elimination status[9]. However, the PB case detection rate was observed of receiving very little success during the same above years with high case load (Table 5). Additionally, the little control achieved in limiting child infection rate (Table 1: 9.83%, 2010-11; 8.94%, 2015-16) indicates the continuance of an undisrupted rate of early infection[10]. Similarly, the case detection rate among the females has risen during the same above years, with about 60% being detected as MB patients [11] by further increasing the disease manifestation risks in the population [12]. The increase in MB female patients implies a late detection possibly due to the causes like lack of awareness, negligence and social stigmatization. The consistent rise in infection rate among the socioeconomically disadvantaged schedule tribes (ST) and schedule castes (SC) sections is also a serious concern. Increase in the visible deformity rate (2.6%, 2006-07; 4.6%, 2015-16) is a matter of concern as it indicates late reporting of MB cases by remaining hidden in the population for long periods [8]. All these aspects highlight that India needs added and intensive efforts in reining in the disease effectively [11].

## Increasing Grade I and II disabilities and limited Reconstructive Surgeries (RCS)

Our analysis finds that India is at present carrying a reported burden of approximate 0.4 million leprosy related disability affected patients of which 87145 and 151172 being in grade I and grade II disability categories respectively along with another reported 150374 facing drug related reaction /neuritis/ insensitive foot conditions. The report shows that there is a more than 75% increase in overall cases related to drug related reactions /neuritis/ insensitive foot conditions only in last 6 years. The 16 endemic states constitute more than 90% of the burden in each of the both disability conditions (Table 3). The problem at state level among the 16 major endemic states is acute in all most all the states except selected few. Similarly, there is a significant increase in drug related reaction /neuritis/ insensitive foot conditions with 85624 numbers of cases by 2010-11 period to 150374 numbers of cases by the year 2016 (Table 3). Our present field study observed that deformity or disability in leprosy carried maximum stigma than the skin patches. Grade II deformity has increased significantly in last six years 3.1% in 2010-11 to 4.6% in 2015-16 (Figure 2). The increase in case load, particular among the underprivileged communities, increases their risk towards Grade II deformity, due to their high vulnerability towards lack of awareness, leprosy attached stigma, cultural beliefs and practices and inaccessibility to healthcare. However, in the absence of any specific data on such disability, our recent limited experience in tribal and rural areas of Odisha highlights the highly increased chances of obtaining a larger number of Grade II deformity cases among such underprivileged populations. However, non-reporting of deformity by health providers in order to avoid the issue of late detection was observed in several cases; as a result, disable patients were found of failing to avail their much-needed medical rehabilitation facilities and RCS. As it can be observed from the Table 2 and Figure 2, the rate of RCS in government facilities during the last six years has significantly been less in comparison to non government agencies [8]. State wise reports provide more contrasting figures regarding RCS scenario among government and NGO agencies, raising serious issues regarding implementation of leprosy care policy. In this context, the case of JS (name changed) provides significant inputs towards understanding the needs of implementation of policies properly.

### The case of JS (name changed): A classic case of neglected deformity

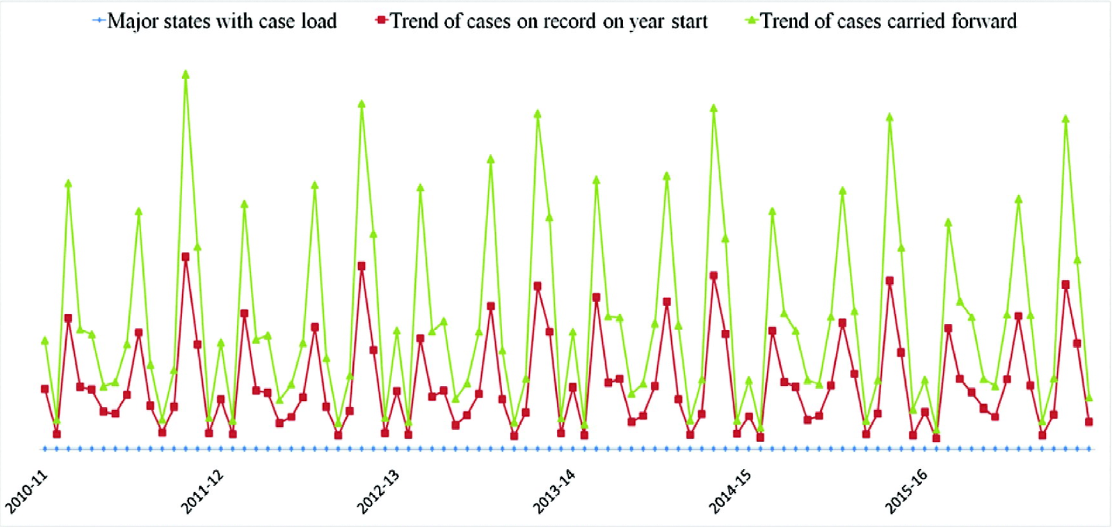
JS was one among the observed several patients with grade II deformity but without any mention in the record book. She was an elderly tribal patient from a remote village. She told that by the time she was brought under the treatment regimen, she had already developed total clawing on both the hands, ulcer in the left foot which was spreading further due to lack of proper treatment with other grade II deformities. She repays her late reporting and treatment as she could not understand the disease in time. But she was eager to receive any treatment that can bring relief to her claw hands and ulcer affected foot. Due to the official non-reporting of her deformity, she could not have received free footwear from the local government medical store. JS is 3-4 months into her MB treatment regimen. The daunting task before her is properly managing her medication every day. Due to total clawing in both the hands, she is unable to open the tablets from the strip, for which she uses some stick or a metal rod by eventually damaging the tablet most of the time. A surgical rehabilitation can possibly bring her a great relief.

Considering such non-reporting of patients with either Grade I or II deformities, proper review at the policy implementation level is the immediate need to overcome the difficulties on the parts of such leprosy patients.

### An increase trend in case detection rate putting tribal and backward sections in the top

Last six years report says there is no consistent pattern of improvement in yearly PR with reporting of large number of new patients (2010-11,126,800; 2011-12,127,295; 2012-13,134,752; 2013-14,126,913; 2014-15,125585; 2015-16, 127,334); it rather shows an observable recently increasing trend (Table 5). It was observed that the larger section of the new cases reported in each year is being forwarded to the next year which is increasing the case burden each year (Figure 4). Furthermore, our field observation found that majority of the case detection activities were taking places towards the end of each year period leading to case burden being shifted to next year which, if taken though out the year will greatly reduce the carry forward patient population. The concerning fact is that the major 15 states (Table 5) show a negative or very less change in the drop in case load from previous year during the last six years periods, while the overall success rate in drop of case load from previous year has been negative or very less in last six years of time (Table 5). This trend is

**Figure 3: The trend of case load in major endemic states (year-wise) and the trend of carry forward of case load (Year-wise)**



similar in case of PB and MB rate also. Eight large states of the fifteen endemic states in 2015-16 report show a close to 1 or more than that number of PB cases per each MB case while the PB:MB ratio stands at 0.94:1 for national level and 0.98:1 for 15 endemic states, highlighting high endemicity of PB type along with the infection rate remaining alarming (Table 5).

Recent years' records of NLEP show the socially and economically disadvantaged sections like tribal and scheduled caste populations with significant increase in leprosy detection rate [2]. Prevalence rate among the tribes in 2010-11 was 14.31% which has increased to 18.79% in last six years. On the other hand, there has no such significant success rate among SC population (PR falling from 18.69% to only 18.57% in last six years) with respect to leprosy control. Twenty one of the 22 districts with ANCDR>50/1,00,000 belong to the four tribal populated states while 38 of the 42 districts with PR>2/10,000 belong to 5 tribal dominated states (NLEP report, 2015-16). Among tribals, though the level of awareness on leprosy is still concerning, however, we observed an improvement in this regard. It remains a mountainous challenge for the late middle aged, women and elderly age group regarding self-reporting of the suspected conditions. On the other hand, inaccessibility of proper leprosy care in many tribal dominated areas is a major obstacle to interrupt the cycle of infection in these communities. A regular surveillance and household-wise survey by trained health workers in endemic villages will help curb the disease menace.

## Urban Stigma

Social stigma is a metaphor to leprosy in India. However, efforts of NLEP through awareness programs and campaigns have been successful in gradually bringing down the stigma level in rural India. As per our recent observations in studied rural areas, social stigmatization is still present there and is largely limited to grade II deformities and disabilities among various other visible leprosy signs. Several people with leprosy patches were observed of living normal lives in different communities though an increase in perceived stigma was observed. On the other hand, urban stigma has increased significantly. It has emerged in two different ways. Firstly, factors like urbanization, increasing education and knowledge about the discriminatory nature attached to the disease have increased the perceived or self-stigma level among the patients. On the other hand, an implicit external stigmatization by the normal individuals was prevalent that they practiced at their individual levels without any explicit behavior with the patients. Considering the limited natures of leprosy stigma studies, multi-centric researches with focus on natures of urban stigmatization will help address the various facets of such complex formulation.

## Rising vulnerability of the poor and the socially marginalized

Leprosy, is known as a 'disease rooted in poverty'. Considering the recent trend in leprosy case detection rate, selected sections of the Indian society like SCs, STs and women facing high social marginalization and poverty are at highest risks of leprosy infection by adding large number of patients to the annual disease load. The latest leprosy prevalence trend highlights a significant rate of rise in the number of cases among SCs and STs [8] while 60% or more female leprosy patients are MB cases [8]. The major reason for such high prevalence is late reporting, attributed by issues like negligence, biases and discrimination. As a result of failure to remove such prejudice in the population, leprosy related health implementation and control programs suffer significantly bringing huge drawbacks for the prevention and cure. Furthermore, it was observed that increased leprosy prevalence among the poor and marginalized sections renders them vulnerable to mass biases and various socio-cultural and economic deprivations by discouraging from spontaneous participation in public activities including those of healthcare. Such aspects need to be mapped in their particular contexts with further reconciliatory steps. Most importantly, lack of proper training to address non-medical aspects, particularly regarding the socio-cultural bearings and concerns involving leprosy, among leprosy workers like ASHAs, block supervisors and other medical professionals and health providers by leading to insensitiveness and casual handling of such aspects were observed to be, many times, critical challenges before NLEP; such approaches were observed of developing complacency among the patients and other leprosy healthcare seekers leading to a discouraging trend towards treatment many times.

## Leprosy and Women

A low female case reporting rate (38.33%) in comparison to males(61.67%) though places the women patients in a possible advantageous state, however, social sufferings among women due to leprosy related issues was observed to be more than men[12,13]. The low social status of Indian women is a crucial factor in causing infection and associated sufferings among them[14]. Our recent findings show low social position of women hugely influences their nutritional status, leading to compromised immunity and early leprosy infection (15) in endemic areas along with the co-morbidity risks like psychosocial stress [16,17]. The low social status results in neglected self-care, delayed treatment, increased MB rate and associated disability by further adversely affecting leprosy control. Additionally, drug reaction rate among the women is also high due to the possible effects of undernutrition and their compromised immunity [18, 19]. Female patients are at higher risk for communicating infection, particularly in the family [14]. India has experienced a rise in the female case detection rate(Figure 2) while, on the other hand, it was observed that 60% of the detected leprosy cases among women are MB patients. So, a gender sensitive approach, which is a highly neglected aspect under NLEP is needed to be pressed as a policy practice under NLEP implementation.

## Roles and statuses of ASHAs and other leprosy-care providers in NLEP and scope for improvement in disease management

The NLEP data shows that out of the large total number of patients detected during the periods 2010-11, 2014-15 and 2015-16, the number of cases detected by the ASHAs has been very less on overall level and even negligible in several states (Table 4). There was found to be very little improvement in involving ASHAs in leprosy elimination program in last 6 years of which we found three possible reasons; first, ASHAs are not adequately and voluntarily participating in NLEP; second, though cases were referred by ASHAs, such cases are not been put in to the records as detected by them; third, patients in several cases avoid ASHAs to avoid the perceived stigma as ASHA in most cases is a neighbor carrying the risk of possible exposure of the identity, and therefore such patients directly approach the leprosy supervisor who is normally a block level health provider carrying less chances of exposure of identity. However, such aspects need further study at primary levels. Besides referrals, Table 4 shows that the number of cases further falls while considering the patients completing their MDT regimen under the ASHAs' supervision. However it needs mention here that as per our field experience, patients undergoing MDT regimen under ASHAs' supervision have a significantly higher rate of completion of the full treatment course than the patients under leprosy supervisors. It was observed during the field study that ASHAs needed proper on-hand training with patients to identify a new suspect leprosy patient which is crucial and mostly lacking in several cases.

Putting the LCDC in this context, it was observed that though several new patients have been brought into treatment regimen through last three years of its implementation, there were many issues needed to be addressed, particularly, when it comes to involving the ASHAs in this campaign. There seems inadequate planning during the implementation of LCDC through village level surveys by involving the ASHAs. First of all, it is an obvious question that as ASHAs are involved in several national and state level health and other program implementations at the village level, there was no distinct plan and policy, at least at ground level, regarding how LCDC planned to handle such regular duties and responsibilities of an ASHA during the period of her involvement for the 14 day period in the LCDC.

Leprosy treatment in post-assimilation era with the vertical disease management been merged into general health care system, largely depends on Accredited Social Health Activists (ASHAs) as the primary agencies in identifying the suspected cases and bringing them under treatment regimen after confirmation. The role of the leprosy supervisor, as block level health care provider has virtually been limited to managing MDT distribution with very limited or nil community visits for case detection. However, in spite of such limitations, every year the country reports such a huge number of case load, while if an active surveillance could be put in place, has a chance of reporting a double or more than that number of new cases remaining hidden or unreported in populations. It is here important that issues like unavailability, inaccessibility, noncooperation and delay by the health care providers at various steps are also not uncommon by causing delayed treatment leading to aggravated disease state and even deformity. So, such gaps need to be bridged by proper interventions and systematic management.

## Proper incentives for the field workers

The present analysis on the basis of the available data finds that there is discrepancy in number of ASHAs receiving financial incentives shown in the reports. As these discrepancies were further examined at field level, it was observed that lack of transparency in distribution of incentives, ambiguity in registering ASHAs against the detected new cases by them, complicacies in incentives distributions after MDT completion are few of the several issues in management of leprosy care at primary level. It was also observed that the ASHA being a resident of the same village in many cases preferred to report indirectly or facilitate the suspected patients around to the leprosy supervisor to protect the person from the possible embarrassment out of the perceived stigma. However, it was observed that such cases in many cases were not considered as cases detected by ASHAs discriminating them from getting the incentives. Most importantly, non-adherence or incomplete MDT treatment regimen of the patients due to several reasons including administrative and management related issues as observed in several cases in our field study, obviously bar the ASHAs to receive the incentives 'on completion'.

On the other hand, as it was observed during the last LCDC, an ASHA was paid only 50 rupees per day (less than a dollar) while she was expected to do a 10 hours job for house-wise search of every members towards identification of new suspected cases. In this process she also had to cover the left over members of the families by revisiting such houses. The issue of coverage is more acute in tribal dominated areas consisting of hamlets. So, there were many resistances observed at the level of Field Level Workers (FLW) with respect to proper implementation of LCDC. So, such large responsibility with long working hours and without a minimal daily wage payment was observed to be a serious de-motivating factor at the field level which needs to be taken care in future. Furthermore, the other government and contractual health care personals engaged to manage and supervise the work of the field surveyors, if any scope is available, need to be administered or compensated appropriately. Furthermore, while training for case detection is given to both ASHAs and AWWs, referral and incentives are offered only to ASHAs. Such shortcomings and gaps in micro planning and implementation levels involving these high value attached programs were observed of having serious bearings on the outcomes by leading to limited success of the basic purpose.

## Serious social issues involving case detection drives

Leprosy case detection drives in India are evolving in various shapes. The latest LCDC structure of such drive adopted a Pulse Polio campaign line. However, with a possible perception of less prevalence of stigma, the case detection drives overlooked the subjective socio-cultural aspects of the disease by emphasizing increased case detection. An increased focus on clinical/medical nature and avoiding the socio-behavioral and cultural contexts is clearly visible at least at practice level. For example, during Leprosy Case Detection Campaign (LCDC), each ASHA was attached with a male volunteer from the same community on hiring basis[3]. It raises serious questions regarding hiring these volunteers and ensuring confidentiality of the patients and the suspect cases. Disclosure of identity can lead to a possible disastrous situation for the person. As the volunteers carry no liability while no viable mechanism is available to the patient to address such issues of social discrimination or stigmatization resulting out of identity disclosure, people were observed of going reluctant for a physical check up in such set up. Additionally, while ASHAs and other health care providers are given orientations, particularly at district or sub-district levels during the NLEP and case detection drives, it is highly important to consider such non-clinical aspects seriously which is a big lacuna as observed in several cases. So, disease control programs need to consider these dimensions while implementing major drives.

## Treatment management becoming a major burden

Post detection management of leprosy is a concern for NLEP in several contexts that needs serious consideration. As we observed during our field research that several patients are going relapsed without any record due to various reasons. Considering the relapse patients with limited risk of infection, the MDT providers in such cases neglect total cure and treatment completion by reporting them as RFT (released from treatment). Furthermore, early detected patients with one or two small skin patches were reported of discontinuance of medication by MDT provider after 2-3 months in few cases. The dangerous trend of idealizing and presenting a fall in prevalence with less number of cases reporting to highlight an improvement in the disease prevalence status is also another visible barrier in disease management. To avoid late detection related compliance, health supervisors are in many cases avoiding the reporting of the deformity. A thorough review may substantially increase the number of disability cases. Such practice of non-reporting of deformity status has serious reparations for patients as they can never avail disability rehabilitation facilities to overcome the difficulties. The management of the ulcer is the other impeding concern for most patients that they fail to overcome. Table 3 shows an increasing number of disabilities along with insensitive foot/drug reaction/neuritis like issues with a rising trend during last six year periods. All these issues though serious challenges before the NLEP from the disease management point of view, the burden carried by each patient at individual level is more significant and concerning as other issues like social stigma, loss of livelihood, destitution come attached with disability to such persons. So, post-detection care and disease governance by focusing at the individual case level than a case load management point of view needs proper and timely evaluation. Official reporting of each and all deformity cases needs utmost priority so that all the patients can avail RCS and other facilities to lead active lives.

## Need of intensive and integrated Information, Education and Communication (IEC) programme

Activities under Information, Education and Communication (IEC) in leprosy elimination campaigns have rarely been integrative in nature. Furthermore, a true and consistent effort through micro-planning to bring all possible actors within the IEC campaign purview will bring exceptional results towards improvement in health seeking behaviors and better quality of life of the patients. As per our latest experience during LCDC, the IEC activities were observed of to be more intense. Furthermore, planning for bringing local agencies like departments under Panchayatiraj, Education, Labour as well as other private and nonprofit organizations in short time span before LCDC like campaigns and drive are bigger challenges, however, with definitive dividends for IEC objectives.

## Sensitization and training of Leprosy care providers regarding case detection

Sensitization of paramedical and other health workers along with local traditional practitioners and healers in tribal and remote areas has highly positive outcomes towards improvement in leprosy management and treatment. As per our recent experience in tribal and rural areas, a similar practice under Revised National Tuberculosis Programme (RNTCP) has brought exceptional results; such approaches are yet to be adopted under leprosy control programme. Several patients in remote areas were observed in advanced state of deformity due to lack of timely adherence to MDT. An expected behavioral training to leprosy health providers is important as the way of communication of information to patients as well as their families regarding the diseases, its nature, attached medical and non-medical issues and treatment procedure and outcomes have serious bearings on MDT regimen and the outcomes. It was observed at the field level that the information given by the leprosy care providers and the way of such communication to the patients many a times leads to introducing the patients to a perceived stigmatization regimen. Similarly, training and sensitization of medical professionals and other health personals in regular interval than only during the case detection drives regarding the treatment and management will bring useful results.

It was observed that primary level training and orientations, particularly in the context of case detection drives like last LCDC involving local health workers including the male volunteers was a daunting task to ensure a proper implementation of LCDC and to successfully identify the suspect cases.

## Social support and alternative sustainable livelihood

Proper social support needs priority for patients with disability to ensure quality lives to them. It has been observed that majority of the patients with grade II disability completely lose their livelihood along with the peer-based social supports. A focused policy providing basic necessary welfare facilities like housing and food security along with other supports like free cycles and shoes needs to be ensured by timely delivery to such beneficiaries. An integrated post treatment social support scheme from all applicable agencies through a single window system will bring a great relief to the patients. Additional initiatives like mobilization, training and individualized counseling for starting own business, livelihood activities and specific arrangements in supporting or financing start-ups are also important to boost their confidence.

## CONCLUSION

Micro-planning needs a true focus on the micro as well as macro level issues in leprosy. Identification of failures in policy implementation and health care, their proper evaluation, along with realizing the confounding obstacles in health care implementation, particularly at local community levels need emphasis. A sustained medical facility attached with proper social support to the patients will significantly improve the quality of life of leprosy patients.

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