



**NLEP Newsletter**

**Quarterly Publication from the House of Central Leprosy Division**

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**MESSAGE FROM DDG (LEPROSY)**

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Empowerment of Leprosy Affected by persons (LAP) as individuals and groups is the present day necessity to integrate and streamline with the mainstream society. Accordingly, the lead story in this issue is Involvement of Association of Persons affected by Leprosy (APAL) in the NLEP activities. In the best practice column Engagement for Transformation- Little Flower leprosy Welfare Association, Sundarpur, Rauxal, Bihar is highlighted and in Success Story feature the High prevalence rate to elimination of leprosy from India was described. In the highlights section National leprosy Conference, New Delhi 2017, WHO informal Consultation on stigma & discrimination against persons affected by Leprosy was included. In the meetings and gatherings section Planning Workshop on action Sparsh Leprosy Awareness Campaign 2018, NLEP Review of status of elimination low Endemic



**Dr. Anil Kumar, DDG(L)**

states, workshop to finalize IEC material for Sparsh Awareness campaign 2018 at Pune were covered. The news about of parliamentarians to free India from leprosy, Hon'ble HFM reviews of NLEP and Monitoring field visits of DDG (L) in West Bengal and Jharkhand etc., were covered under the section 'News around' .In the spotlight and photo gallery photographs from National leprosy Conference were added. I hope readers will find this issue of newsletter very useful and look forward for your constructive feedback.

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## LEAD STORY

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### **Involvement of persons affected by leprosy in the various activities of NLEP**

when leprosy is completely curable with MDT (multi drug therapy), but some parts of India still uphold the belief that leprosy is a divine curse, a punishment of the past sins, due to this stigma and discrimination prevailing in the society, affected people were isolated from their family and society and nobody cared to rehabilitate them in those days and they never had the formal representatives who can take a stand for them.

Association of People Affected by Leprosy (APAL) is a representative body of people affected by leprosy, founded in year 2006 with encouragement and support of Nippon Foundation, Japan by Mr. Sasakawa's. Before APAL person affected with leprosy did not have any formal representatives among them who can represent Person Affected, as Person Affected are main stakeholder (beneficiaries/end user) of National Leprosy Eradication Programme (NLEP). APAL is a registered society (2013) and members of APAL mostly are leprosy cured people who are expected to know

the real issues being faced during the course of disease.

APAL provides a platform to the person affected with leprosy to discuss their issues and take up matters relating to their rights and entitlements at various *fora* at centre and state govt. level. Central Leprosy Division, Govt. of India utilized the existence of APAL and provide the opportunity to affected people to get involved in various activities of National Leprosy Eradication Programme (NLEP) at various levels of program cycle like Planning, implementation, feedback, gap identification, monitoring and evaluation.



**Planning:** CLD involved affected person through APAL in decision making and planning activities of implementation strategies at various level meetings like high and low endemic areas meeting, workshop of LCDC, and monthly meetings

of Gram Sabha for planning SPARSH activities. Person affected were also involved in preparations of WHO Guidelines, Principal and Guidelines of UNHRC, Geneva and SPARSH guidelines. SPARSH guidelines itself advocates to involve Person Affected at all level of meetings i.e. National, State, District and block level.

**Implementation:** development of leadership among the youth in grass root level in implementing SPARSH and LCDC activities. PAL get involved by CLD in identification of spots (school, rallies, and gram sabha) and mouth to mouth publicity for SPARSH awareness campaign at block and district level.

Participate in National & International deliverance of issues of leprosy and raised voice for equal participation, equal rights and opportunities like National Leprosy conference 2017 and presented a session “Nothing about us without us”, release of SPARSH guidelines by person affected with leprosy.



“Release of SPARSH guidelines by APAL representative”

**Feedback and gap identification:** APAL identified issues during activities of LCDC, SPARSH and on rights of land ownership, educational facility, employment opportunity for youth and skill development.

**Monitoring & Evaluation:** representatives of APAL participate in annual review meetings, SLO-national meetings and also participated in evaluation of LCDC activities of NLEP in many state along with state and center officials. APAL is identifies as one of the stakeholder manager’s programme with Centre Leprosy Division, NLEP, Govt. of India.

Involvement of APAL in such activity of NLEP is a cost effective way of empowering the Person Affected by involving the end user of the programmes. As affected people are already motivated, aware and know the issues of affected people faces. PALs are the best people to do advocacy of the programme because of their zeal.

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### **BEST PRACTICES**

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#### **Little Flower Leprosy Welfare Association (LFLWA), Sundarpur, Rauxal , Bihar**

This is about a real-time experience in strong engagement for 15 years between Little Flower Leprosy Welfare Association (LFLWA) and people of Sundarpur, Rauxal, Bihar and donors, the government and NLEP agencies.

As a result of a strong engagement between the LFLWA and the people of sundarpur, Rauxal, Bihar as many as 54466 people affected, besides 40450 disabled people got benefited .The Bed strengths of Hospital is 140 with few supportive staff. A total RS 175435060 Rs. was utilized since last 15 years. 6703 footwear was distributed to the eligible patients.



Founder Fr/Br Christo Das who gave his life for affected people.

A total 270 and their family members were employed and 230 persons are getting a welfare allowance with an average income to the employer Rs. 3500 and average amount of allowance per beneficiary is Rs. 700. They generate Rs. 4 million annual gross incomes in a diary form with 70 cows with an average yield of 200 litres milk daily.

More affected persons and their families would be need of jobs and the income of employer would be more so does the average allowance to Person Affected.

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### **SUCCESS STORY**

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### **Journey from high prevalence rate ( 58/10000 )to elimination of leprosy India**

Even though the National leprosy Control Programme was launched in 1955 the actual facts and figures were known only after 70s .There were 40 lakhs leprosy patients in India (giving a prevalence rate of 58/10000 population) in 1982. The leprosy patients were treated with Dapsone- monotherapy for an indefinite till patient became negative for AFB in skin smear. Since the patients started their treatment at the later stage of the disease, deformities were very common due to leprosy. Deformities accompanied with age old misconceptions about the disease added cumulative effect on the leprosy case detection that resulted in hiding the disease for fear of stigma and discrimination.

There was a major breakthrough in the treatment of leprosy in the form of Multi-drug Therapy (MDT). Multidrug therapy was introduced in 1982 with Rifampicin, clofazimine and dapsone. This regimen was adopted throughout the country with remarkable success. A very rapid and steep fall in prevalence of the disease was seen and the fall was so spectacular that by 2005, the prevalence came down to less than 1/10000. Rate less than 1/10000 indicates a state of “elimination” of the disease, when the disease ceases to be a public health problem. This was indeed a landmark achievement.

Although prevalence has come down at national and state level, new cases are being continuously detected and

they have to be provided quality leprosy services. This required active Detection and prompt case management at the early stage, Disability Prevention and Medical Rehabilitation (DPMR) through physiotherapy and Reconstructive surgeries.

At the welfare front greater awareness about leprosy enabled replacement of lepers act 1898, the word leper now become derogatory and replaced with Person affected by leprosy (LAP). Now the problems of leprosy affected persons (LAP) are seen from human rights angle.

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### HIGHLIGHTS

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#### **National Leprosy Conference (NLC) 2017.**

The National Leprosy Conference (NLC) was held from 5-7th Dec 2017 at Holiday Inn, Aerocity, Delhi. NLC supported by World Health Organization (WHO) International federation of Anti-Leprosy associations (ILEP-India), Novartis, The Nippon Foundation Japan, Sasakawa-India Leprosy Foundation, Indian association of Epidemiology, Association of person affected by Leprosy and other NGOs. Objectives of the conference was to showcase the best practices within and outside the country to enhance programme advocacy, recognize and encourage efforts of leprosy work force, acquire inputs for effective implementation of the programme, establish linkages among various national and international partners and to learn innovations.

About 300 national and international delegates participated and involved in the conference. There were 10 themes in which various stakeholders like PAL, ASHA, ANMs, BPHN, DLO, SLO, MO, Public health experts, specialists (dermatologist), NLEP consultants and representatives from various development partners presented their work and experience with person affected with leprosy. This time front line workers like ANMs and ASHA shared their experience in terms of challenges, issues and best practices they faced during Case Detection at grass root level – reaching to the last affected person.



The conference deliberated on the issues like mainstreaming of PAL, case detection at grass root level –reaching last affected person. Issues, challenges and best practices pertaining to effective programme management and coordination which includes effective implementation, supervision and monitoring at block, district and state levels. Matters on international collaboration and implementation of recent innovative practices for leprosy elimination in India also discussed. Discussion on potential roles of

professionals like public health experts, dermatologists, social scientists and civil societies for elimination of leprosy from India was also part of the deliberations.

**WHO expert group's informal consultation on stigma and discrimination against leprosy affected persons from 14-16<sup>th</sup> November 2017.**



The WHO expert Group's meeting on "Informal consultation about stigma and discrimination against leprosy affected persons" was held from 14<sup>th</sup> -16 November 2017, in which Participants from 9 (nine) different WHO regions involved in the National Leprosy Programmes associated with stigma and discrimination against leprosy, Members of Parliament Members of WHO technical advisory group on leprosy, representative of leprosy affected persons attended the meeting. The main objective of the meeting was to discuss legislations that allow stigma and discrimination against leprosy, to discuss social mobilization, empowerment interventions to reduce stigma and discrimination and to promote inclusion of persons affected by leprosy and to improve their access to service delivery.

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**EVENTS & GATHERINGS**

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**Planning workshop on Sparsh Leprosy Awareness Campaign 2018.**

After the successful implementation of Sparsh awareness campaign (SLAC) 2017, where Nation-wide Gram Sabha meetings were held in 60% of villages India on 'Anti Leprosy Day, i.e., 30<sup>th</sup> January 2017 with an objective to increase the awareness among people about leprosy and to increase the public participation to eliminate leprosy from India. Inspired by the huge success of this campaign the Govt. of India decided to organize Sparsh Awareness Campaign (SLAC) during 2018 also. In this connection a National workshop on IEC for SLAC was conducted on 28<sup>th</sup> December 2017 in **Yashwantrao Chavan Academy of Development Administration, Pune, Maharashtra**. The workshop was attended by Mr Navdeep Rinwa, Joint Secretary to the Govt. of India in the Ministry of Health & Family Welfare and Dr Anil Kumar, DDG (L) from Central Leprosy Division, besides State leprosy Officers of the States/UTs, Representatives from Regional Offices of Health & Family Welfare, world health organization coordinators of the partner organizations, Directors of Central Leprosy Training & Research Institutes, International Federation of Anti-Leprosy Associations (ILEP) and other eminent experts from the field. The workshop finalized the mascot SAPNA and finalized the detailed plan of action etc.

**Review on status of elimination in low endemic states**

Henceforth Elimination efforts in these states should be focused more towards district specific plans according to their endemic status and recent initiatives taken at the centre like Leprosy Case Detection Campaigns (LCDC), Focused Leprosy Campaigns (FLC), Special Plan for Hard to Reach Areas etc., may be percolated down to the district, block and village levels.



**National workshop to finalize IEC messages for Sparsh leprosy Awareness Campaign (SLAC) 2018.**

The messages, Script, the format of IEC materials to be used in ensuing Sparsh Leprosy Awareness Campaign (SLAC) 2018., and guidelines on their use was finalized in a central level workshop held at Pune, Maharashtra on 27<sup>th</sup> December 2017. The workshop was attended by Dr Anil Kumar, DDG (L) from Central Leprosy Division, Mr Navdeep Rinwa, Joint Secretary to the Govt. of India in the Ministry of Health & Family Welfare, besides State leprosy Officers of the states/UTs, Representatives from Regional Offices of health & family welfare, world health organization coordinators of the partner organizations, Directors of Central Leprosy Training Institutes, International

Federation of Anti-Leprosy Associations (ILEP) and other eminent experts from the field.



**Forum of Parliamentarians to free India from leprosy.**

Sasakawa India Leprosy Foundation (SILF) is closely working with “Forum of Parliamentarians to free India from leprosy” headed by MP and ex-Railway Minister, Mr. Dinesh Trivedi and ex-MP, Mr. Madhu Gaud Yaskhi, the forum cut across party lines and aims to free India from leprosy. The members offer their good offices and influence in the legislature to raise awareness about leprosy and bring about changes that ensure basic human rights of the leprosy-affected persons. They also facilitate linkages the existing national and state government welfare schemes and the leprosy-affected persons in their constituencies. The Forum has blessing of Hon’ble ex-Speaker of Lok Sabha, Mrs. Meira Kumar and the Hon’ble Former Vice President of India, Mr. Hamid Ansari. Till date there are 53 members from different states and different political parties. In 2014-15, under the leadership of Mr. Trivedi and Mr. Yaskhi, a core committee was formed to plan on more effective and outcome-based engagement of the MPs in

this initiative. Each and every member of the newly elected parliament was approached and informed of the activities of the Forum, and the forum met twice during the winter session of the parliament. The MPs showed keen interest to visit the colonies and interact with persons affected with leprosy living in those colonies.

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### **NEWS AROUND**

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#### **Hon'ble Health & Family Welfare minister reviewed the progress of NLEP**

Hon'ble Minister of Health & Family Welfare Shri J.P.Nadda reviewed the progress of National Leprosy Eradication (NLEP) on 17/11/2016.

#### **Application of geographical information systems (GIS) mapping technique for planning & monitoring of NLEP.**

Geographical Information Systems (GIS) mapping techniques just like Google maps are recognized as potential transformational devices to Public Health Programmes like NLEP to analyse epidemiological data (incidence and prevalence rates) on their trends and inter-dependences which would otherwise lie hidden if the data shown in simple tabular form. In the NLEP, GIS was used in the analysis of annual data from all the states and Union Territories and transformed into visualizations. District-wise data pertaining ANCDR and Prevalence Rate of leprosy transformed into visualizations which was hitherto carried manually and presented in tabular form. Pinpointing high endemic districts in

a color coded fashion helped the CLD in micro planning for the special campaign initially in 50 high endemic districts across seven states in 2015-16 and expanded later in 2016-17 to 163 districts across 20 States. Since the pockets with adjacent high endemic districts could be easily discerned visually, the programme planning for the campaigns was more effective in terms of cost and its output.

#### **Monitoring Visit of DDG (L) to West Bengal and Jharkhand**

Dr Anil Kumar, DDG (L) visited West Bengal and Jharkhand from 07/11/2017 to 11/11/2017 as part of monitoring of LCDC activities at the state and district level. He and his team visited Purulia, Bankura and Hoogly (West Bengal) and Sareikela and Jharkhand. DDG (L) suggested some corrective actions in the course of LCDC implementation in these states. On the last day of visit a debriefing session by the Director State health Mission.

#### **Dr Anil Kumar, DDG (L) visited RLTRI, Gouripur**

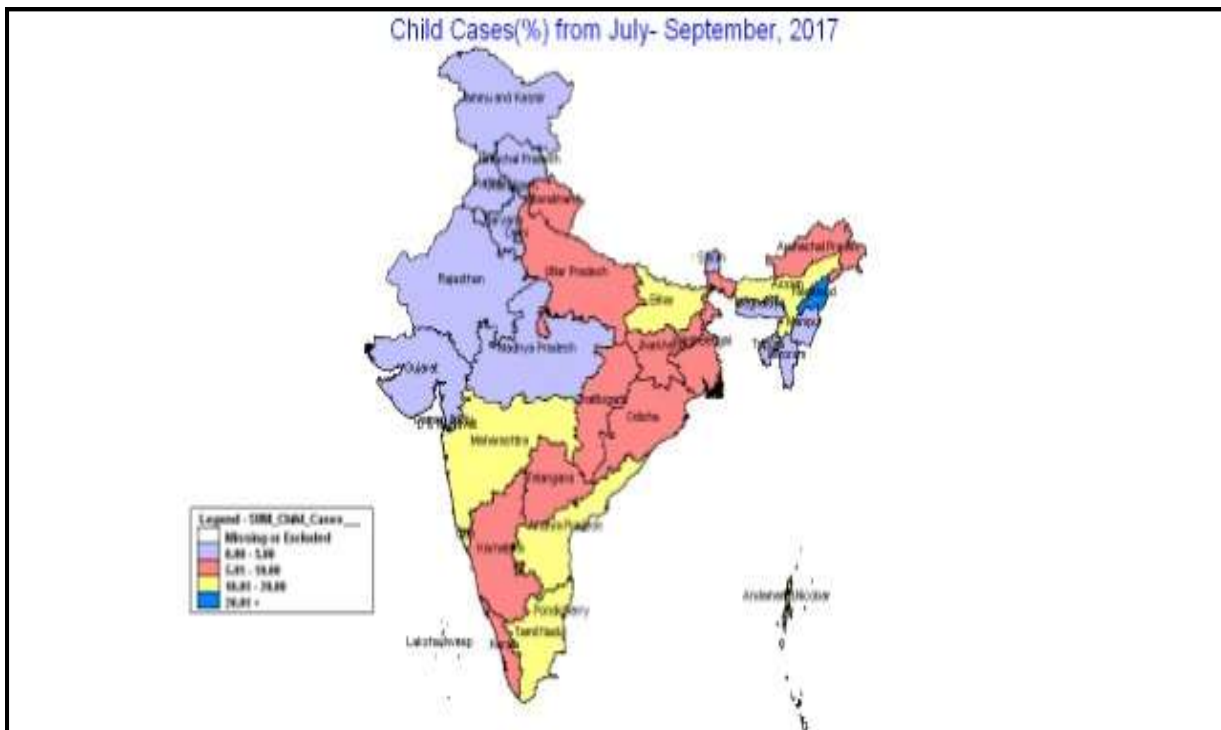
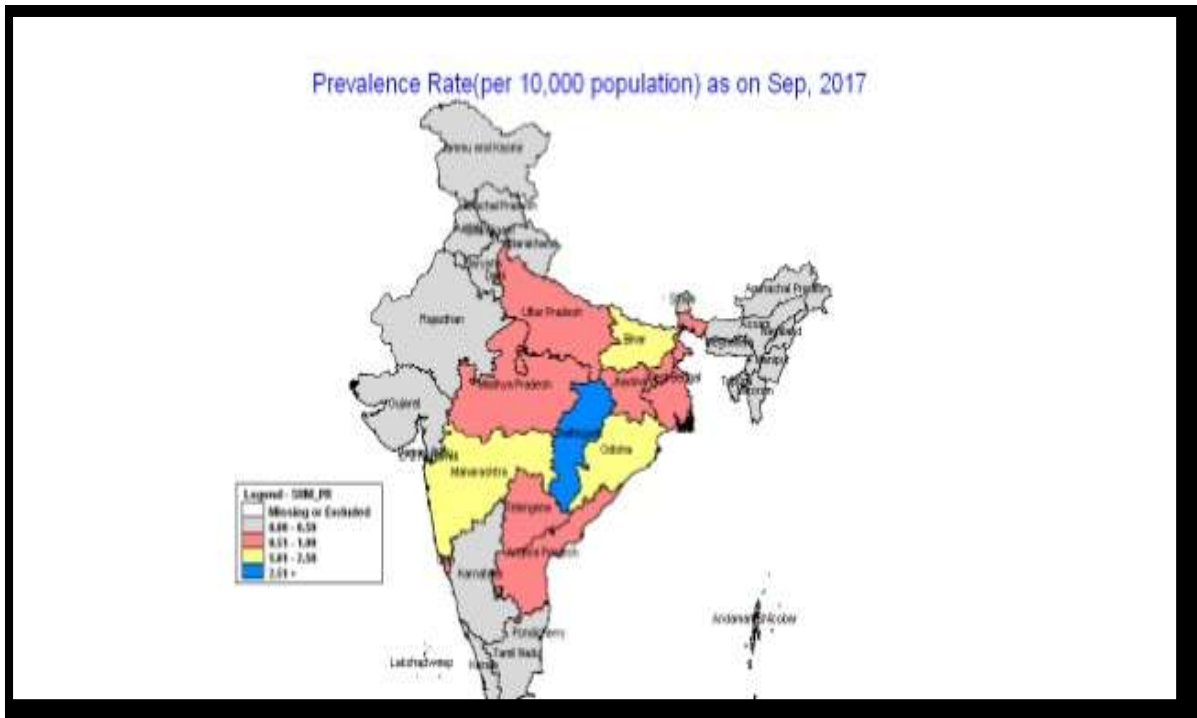
Dr Anil Kumar DDG (L) visited RLTRI, Gouripur on the sidelines of his visit to West Bengal and Jharkhand and interacted with the officers and staff, Dr Pritam Roy WHO NTD coordinator for the state of West Bengal made a presentation about the new initiatives taken by the WHO in the recent past. At the end of the programme DDG (L) directed the officers and staff of the institutes to provide their support in the implementation of new innovations.



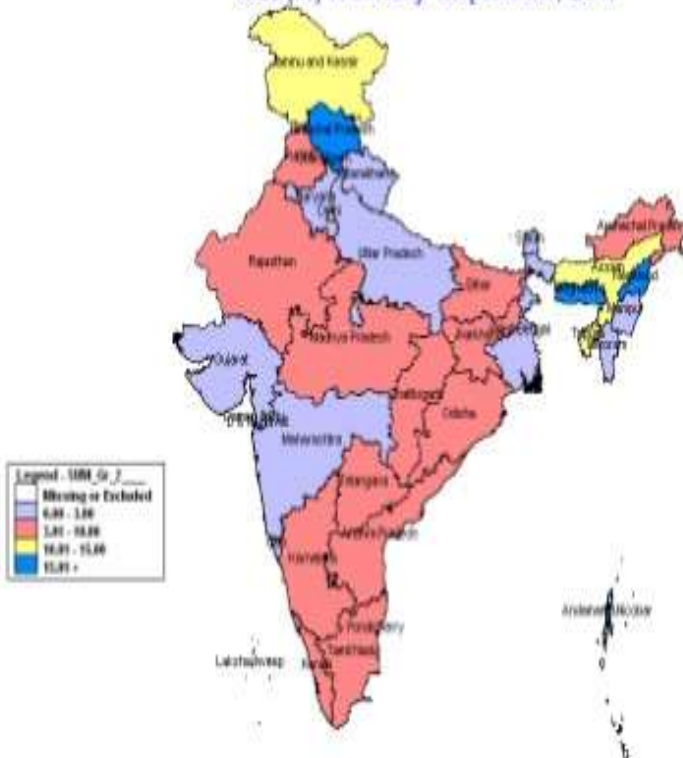
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## SPATIAL DATA

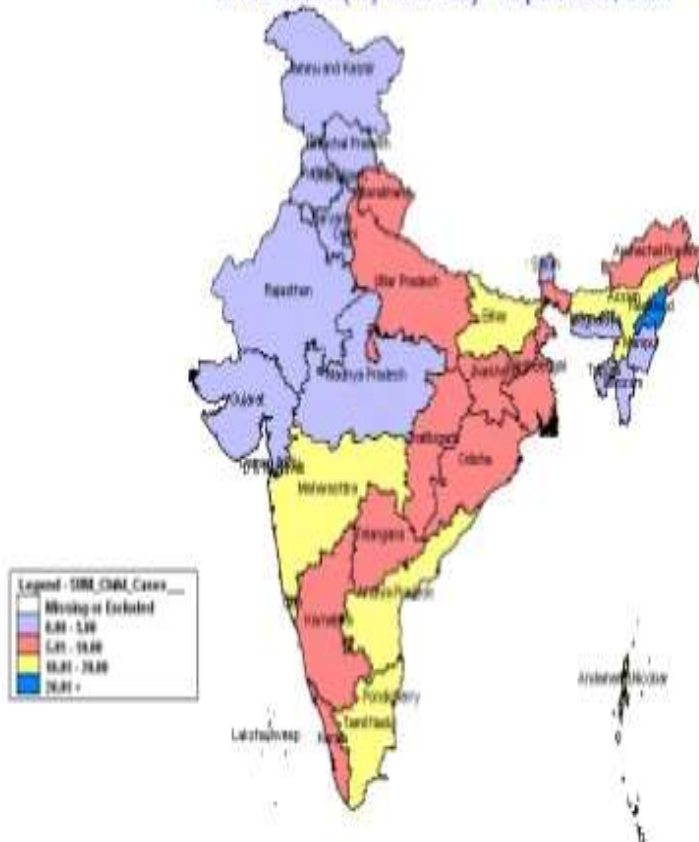
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G2D(%) from July- September, 2017



Child Cases(%) from July- September, 2017



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## SPOTLIGHT/ PHOTO GALLERY

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