After the Diagnosis: Leprosy-Affected Persons and Their Families in Odisha's High-Burden Districts

On World Leprosy Day 1999, India announced that it had achieved elimination of leprosy as a public health problem — defined by the World Health Organization as a prevalence rate of less than one case per 10,000 population. The announcement was accurate at the national level, and....

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The announcement was also, in a specific and important way, dangerous.

In 2005, India achieved elimination at the national level for the second time, having briefly exceeded the threshold again. The National Leprosy Eradication Programme (NLEP) declared this a success and progressively dismantled parts of the vertical disease-control infrastructure — specialised leprosy hospitals, dedicated leprosy workers, separate case detection systems — integrating leprosy response into the general health system.

But elimination is a statistical threshold, not an eradication. It says nothing about the states, districts, and communities where the disease continues to be transmitted. And it says nothing about the hundreds of thousands of people who were already affected — who had already developed nerve damage, limb deformity, and disability before or after the elimination declaration, and who continued to live in communities that had centuries of stigma embedded in how they were treated.

India still detects approximately 1.14 to 1.27 lakh new leprosy cases annually. This is 55–60 percent of the global total. Odisha is among the five states with an Annual New Case Detection Rate (ANCDR) above 10 per 100,000 population — alongside Bihar, Chhattisgarh, Madhya Pradesh, and Telangana. As of 2024–25 NLEP data, Odisha's prevalence rate sits above the national average, and several of its districts — particularly in the southern tribal belt — continue to have pockets of hyperendemicity where transmission is active.

This Convergence Note is about people. It is about the leprosy-affected person in Koraput or Rayagada who received a diagnosis, completed treatment, and returned to a village that still treats them as untouchable. It is about the child whose parent has visible disability from leprosy, and who faces discrimination at the school gate. It is about the cascade of legal, social, and economic exclusions that follow a leprosy diagnosis in rural Odisha — and about what the scheme architecture, NGO programmes, and CSR investment can do about it.

Odisha's Leprosy Burden: Where and Who

Odisha's disproportionate leprosy burden is concentrated in the same geography that carries its deepest structural disadvantage: the southern tribal districts. Koraput, Rayagada, Nabarangpur, Kalahandi, Malkangiri, Kandhamal, and Gajapati districts account for a substantial share of the state's new case detection. This is not coincidental.

The epidemiology of leprosy is linked to crowding, poverty, malnutrition (which reduces immune response to Mycobacterium leprae), and delayed care-seeking. The tribal communities of southern Odisha — where forests and hills create geographic isolation, where the formal healthcare system has historically had minimal penetration, where nutritional deficits are among the worst in the country — present all of these risk factors simultaneously.

The research literature on leprosy in Indian tribal communities (published in the Indian Journal of Medical Research, among others) documents a consistent pattern: Scheduled Tribe populations bear a disproportionate share of new leprosy cases relative to their share of total population. In states with high ST concentration and active transmission — Odisha is a clear example — the disease burden is concentrated in tribal hamlets that are furthest from diagnostic facilities, where case detection is delayed, and where disability at the time of diagnosis (Grade 2 disability, meaning visible deformity) is therefore higher than in populations with earlier access to healthcare.

What does this mean in practice? A Grade 2 disability at diagnosis means the person's nerve damage has already progressed to visible disfigurement — typically clawing of the hand, foot drop, or ulceration from loss of sensation. This disability is what drives the worst social consequences. A person diagnosed with leprosy who receives Multi-Drug Therapy (MDT) before disability develops has a disease that is cured completely, leaves no marks, and produces no physical limitation. A person who reaches diagnosis only at Grade 2 — because the nearest health centre is two hours by foot and the symptoms were managed with home remedies for two years — is cured of the infection but carries permanent disability that marks them for life.

The NLEP data for 2024–25 shows that 638 districts nationally have achieved district-level elimination (prevalence rate < 1/10,000), up from 542 in 2014–15. The districts that have not yet achieved this threshold are disproportionately in the high-burden states — and within Odisha, the districts that continue to have above-threshold prevalence are in the southern and tribal belts where detection infrastructure is weakest.

The Cascade of Exclusion

The social consequences of a leprosy diagnosis in rural Odisha do not follow a linear logic. They accumulate, compound, and self-reinforce across multiple domains of life simultaneously.

Social Exclusion

Leprosy stigma in India has a history that predates modern medicine. Religious texts, caste codes, and community practices across multiple traditions associated leprosy with ritual pollution, divine punishment, and the necessity of separation. These associations have proved extraordinarily durable — surveys conducted by NGOs working in leprosy-endemic districts consistently find that community members maintain social distance from leprosy-affected persons even when they intellectually accept that the disease is cured.

A cured person with visible disability from leprosy — a clawed hand, a scarred face, a foot that drags — cannot pass. The disability is permanent. The social distance persists. In many rural Odisha communities, a leprosy-affected person eats separately, is excluded from shared water sources in some cases, and is denied the physical contact that is normal social currency in close-knit communities.

Marital and Familial Consequences

Until 2019, leprosy was a ground for divorce under four central personal laws in India (the Hindu Marriage Act, the Dissolution of Muslim Marriages Act, the Divorce Act, and the Special Marriage Act). The Personal Laws (Amendment) Act, 2019, removed leprosy as a ground for divorce — a reform the Supreme Court had pushed for, following a petition by advocate Soumya Chakraborty, on the grounds that the provision was discriminatory against persons with disabilities and perpetuated stigma.

The law has changed. Social practice has not changed proportionally. In rural Odisha's leprosy-endemic districts, spousal abandonment following leprosy diagnosis — particularly of women — remains a documented reality. The affected woman who is left by her husband is in the worst possible convergence of vulnerabilities: she has lost her primary income source (if she was not already working), she may have lost her home (in cases where the husband's family is the household), she faces social exclusion from the community, and she is now responsible for children who face discrimination because of their parent's condition.

Legal Discrimination That Still Exists

Despite the 2019 reform on divorce grounds, India retains numerous other discriminatory laws targeting leprosy-affected persons. A study by the Law Commission of India identified over 100 such provisions nationally. Odisha is cited among the states whose laws prohibit leprosy-affected persons from contesting local body elections. The Motor Vehicles Act provision restricting driving licences for leprosy patients has been retained in some interpretations. The

Indian Railway Act provisions regarding travel by leprosy patients have not been repealed.

These laws are inconsistently enforced and inconsistently known — but their existence signals a systemic legitimisation of discrimination that has real social effects. When a law says a person with leprosy cannot contest a gram panchayat election, it tells that community something about how the state values that person.

Education Exclusion for Children

The children of leprosy-affected persons face a specific form of secondary stigma that has received less attention than stigma against affected persons themselves. In communities where leprosy stigma is active, children of affected parents face exclusion from peer groups, discrimination from other parents, and sometimes explicit discouragement from school teachers or administrators who reflect community attitudes.

This is not universal — in districts where NGO-led awareness programmes have been sustained, and in urban or semi-urban areas, this discrimination is less pronounced. But in remote tribal habitations of Koraput or Malkangiri, where the nearest PHC may have a doctor for three days per week and where community norms have been less touched by awareness programming, a child whose parent has visible leprosy disability is navigating social exclusion as a daily reality.

The Scheme Architecture: What Exists

National Leprosy Eradication Programme (NLEP) / Mission Madhavbaug → Now Integrated

The NLEP operates through Odisha's state health department under the NHM umbrella. Key services:

- **Multi-Drug Therapy (MDT):** Free, at all PHCs and CHCs. MDT for Paucibacillary leprosy is a 6-month course; for Multibacillary, 12 months. MDT is curative — completing the course eliminates the infection completely.
- **Nikusth 2.0:** The digital case tracking system for leprosy, launched 2023, allows recording, reporting, and monitoring of individual patient journeys. Better data quality; mixed implementation in remote districts.
- **LCDC (Leprosy Case Detection Campaign):** Annual active case-finding campaigns that bring detection teams to communities rather than waiting for self-reporting. These campaigns are critical in districts where health-seeking is delayed — they reduce the proportion of cases detected at Grade 2 disability.
- **MCR Footwear and Aids/Appliances:** Microcellular rubber footwear, which prevents plantar ulceration in patients with loss of sensation in the foot, is provided free under

NLEP. Self-care kits for wound management are also provided.

- **Reconstructive Surgery (RCS):** For patients with established deformities, reconstructive surgery (to correct claw hand, foot drop, or lagophthalmos) is available at designated medical college hospitals. The surgery does not restore function fully but significantly improves quality of life and reduces the visual salience of disability.
- **ASHA-Based Surveillance for Leprosy Suspects (ABSULS):** Trained ASHAs in endemic blocks are tasked with identifying suspected leprosy cases in their communities and referring them to the PHC. This is the most important community-level detection mechanism and its quality is highly variable.

PM-JANMAN

The PM Pradhan Mantri PVTG Development Mission (PM-JANMAN), announced in the Union Budget 2023, includes leprosy-specific provisions for PVTGs under the Ministry of Health and Family Welfare component — specifically listing leprosy detection and treatment among the health services to be intensified in PVTG habitations. This is significant for Odisha, which has 13 PVTGs, and where PVTG communities in Koraput, Rayagada, and Kandhamal are among the highest-burden communities.

PM-JANMAN implementation in Odisha is at an early stage, and the translation from central announcement to district-level action has been uneven.

The Persons with Disabilities Framework

Persons who have permanent disability from leprosy are entitled to the protections of the Rights of Persons with Disabilities (RPwD) Act, 2016, which covers 21 disability categories including leprosy-cured persons. Entitlements under RPwD include:

- Disability certificate (UDID — Unique Disability Identity Card)
- Reservation in government employment (4% of vacancies reserved for persons with benchmark disabilities)
- Priority in poverty alleviation schemes
- Educational accommodations
- Social security schemes (state-level disability pension)

The critical access point is the Unique Disability Identity Card (UDID), issued by the District Medical Board. In practice, many leprosy-affected persons in rural Odisha have not applied for the UDID because they are unaware of it, because the application process requires travel to the district headquarters, or because the disability certificate application process requires documentation they don't have.

The Odisha government administers a Madhu Babu Pension Yojana (MBPY) which covers persons with disabilities above 40 percent. Leprosy-affected persons with Grade 2 disability typically qualify. The pension amount is Rs 500 per month (as of 2024) — a modest sum but meaningful for a person who has lost their ability to do the manual labour that was their primary livelihood.

NALSA Scheme for Victims of Trafficking and Marginalised Persons

The National Legal Services Authority (NALSA) has a specific scheme for leprosy-affected persons — the NALSA (Legal Services to the Persons Affected with Leprosy) Scheme — that mandates District Legal Services Authorities to provide free legal services to leprosy-affected persons and their family members. This includes assistance with disability certificate applications, pension claims, protection from discrimination, and matriomnal disputes.

In practice, DLSA legal services reach leprosy-affected persons only when there is an NGO or ASHA acting as a connector — leprosy-affected persons in remote districts are not walking into DLSA offices independently.

What's Actually Working: ASHA Surveillance and NGO Presence

Two factors consistently separate districts with better leprosy outcomes from those with worse ones in Odisha: active ASHA surveillance, and sustained NGO presence.

Where ASHAs are trained, supervised, and incentivised for leprosy case referral, detection happens earlier and disability rates at diagnosis are lower. The ASHA incentive for leprosy case referral under NLEP is a modest Rs 250 per confirmed new case referred — enough to motivate if the ASHA is well-supervised, not enough if leprosy detection competes with the many other ASHA tasks.

NGO presence matters because the cascade of exclusion following diagnosis is not a medical problem — it is a social, legal, and economic problem that the health system cannot address. NGOs in this space do the work that bridges the NLEP's medical mandate with the affected person's complete life situation:

- Facilitating UDID applications
- Connecting affected persons to MBPY pension
- Supporting children's school access
- Providing community awareness to reduce stigma
- Legal aid connections through DLSA
- Livelihood support for persons with limited manual capacity (tailoring, small trade, poultry, goatery where hand grip permits)

The most effective NGOs working in leprosy in India — The Leprosy Mission Trust India, Association for People with Disability (APD), and others — have demonstrated models that combine health-system partnership (working alongside ASHA and PHC staff) with community-based rehabilitation (CBR) that addresses the social and economic dimensions.

In Odisha, the NGO coverage of leprosy-endemic areas is thin relative to the need. Districts like Malkangiri, Nabarangpur, and Koraput have among the highest case detection rates and among the weakest civil society presence. This gap is both a problem and an opportunity for NGOs and CSR programmes willing to work in difficult geographies.

For NGOs: The Programme Architecture That Works

An effective NGO programme for leprosy-affected persons in an Odisha endemic district has three integrated streams:

Stream 1: Health system augmentation. Supporting LCDC campaigns with community mobilisation (getting people to come to detection camps), supporting ASHA supervision on leprosy referral, and ensuring MDT completion rates (patients who start but don't complete MDT remain infectious and develop drug resistance). This requires working within, not around, the PHC and ASHA system.

Stream 2: Social protection linkage. UDID registration, MBPY pension enrollment, Ayushman Bharat card (many leprosy-affected persons are eligible but not enrolled), ration card entitlements, and for women who have been abandoned, access to DWCRA (Development of Women and Children in Rural Areas) or Mission Shakti SHG membership as an economic entry point.

Stream 3: Community awareness and norm change. This is the longest cycle and the most critical. A programme that gets the medical response right but doesn't change community attitudes produces cured people who still eat alone. Stigma reduction requires sustained community engagement — working with panchayat members, school teachers, AWW networks, and religious leaders to shift the understanding of leprosy from a curse/pollution framework to a medical one. This is not accomplished in a single awareness camp.

For CSR: Why Leprosy Is an Underinvested Space

Leprosy programming is among the least funded areas in Indian CSR, despite India carrying more than half the world's leprosy burden. There are several reasons for this: the disease is associated in the public mind with historical imagery that feels dated; "elimination" announcements have created the perception that the problem is largely solved; and the affected population is concentrated in the least visible geographies (remote tribal districts) and the least powerful social groups.

The funding gap is real and well-documented. International organisations like The Leprosy Mission, ILEP members, and American Leprosy Missions have historically carried much of the civil society response in India, particularly in post-MDT rehabilitation and stigma reduction. Domestic CSR and philanthropy have been largely absent.

The investment case for CSR in leprosy is grounded in three arguments:

The TB analogy. TB was another disease considered "under control" that received renewed attention when its burden and drug resistance crisis became undeniable. The same pattern applies to leprosy — a disease that is technically manageable but is being managed poorly in the communities that carry it most heavily. Early investment avoids a larger crisis.

The disability-to-dignity pipeline. A leprosy-affected person with Grade 2 disability who receives reconstructive surgery, UDID certification, MBPY pension, and a sustainable livelihood is a person who has moved from disability to dignity. The cost of that complete intervention — surgery plus social protection linkage plus community rehabilitation — is modest relative to most CSR programmes. The impact is irreversible.

The community exclusion multiplier. Leprosy-affected persons' children are at elevated risk of educational dropout, poverty, and social exclusion. Each generation of affected families that is not supported creates a downstream cohort of excluded young people in Odisha's most disadvantaged districts.

Schemes at a Glance

Scheme	Relevance	Nodal Department
NLEP / MDT	Cure (free Multi-Drug Therapy at PHC)	Health & Family Welfare / NHM
LCDC	Active case finding in communities	Health & Family Welfare
MCR Footwear / Self-Care Kits	Disability prevention, wound management	NLEP / NHM
Reconstructive Surgery (RCS)	Deformity correction at medical college	NLEP / NHM
RPwD Act 2016	Legal rights, employment reservation, UDID	Social Security & Empowerment
UDID (Unique Disability ID)	Disability certificate, gateway to all PWD entitlements	Social Justice Department
Madhu Babu Pension Yojana	Rs 500/month disability pension (Odisha state)	Odisha Social Security Dept
Ayushman Bharat PMJAY	Health coverage for eligible households	Health & Family Welfare
Mission Shakti (SHG)	Economic entry point for affected women	Women & Child Development
NALSA Leprosy Scheme	Free legal services via DLSA	Justice / NALSA
PM-JANMAN	PVTG-specific health and welfare	Tribal Affairs Ministry

The Person Behind the Statistic

Somewhere in the forested interior of Koraput district, a 42-year-old man is hiding his right hand when he goes to the market. His three fingers are contracted — the classic claw hand of untreated multibacillary leprosy — and he knows that if the vegetable seller sees them, she will not take money from his hand directly. He completed his MDT two years ago. He is cured. The bacteria are gone. But the nerve damage is permanent, and so is what it means in his village.

He doesn't know that his disability qualifies him for a UDID card, which would qualify him for a disability pension, which would qualify him for priority housing under PMAY, which would qualify him for a surgical consultation that might partially restore his hand function. He doesn't know these things because no one has told him, because the ASHA in his village was not trained in post-cure rehabilitation pathways, because the NGO whose outreach he might have reached left the district when their funding cycle ended.

This Convergence Note is written for the practitioners and the funders who can change that outcome — not for one man in Koraput, but for the thousands like him in every high-burden district in Odisha. The disease can be cured. The exclusion is a choice that policy, programme, and community engagement can undo.

Sources: National Leprosy Eradication Programme (NLEP) — dghs.mohfw.gov.in; Indian Journal of Medical Research — "Epidemiological Scenario of Leprosy in Marginalized Communities of India: Focus on Scheduled Tribes" (2023); Wikipedia — Leprosy in India; PIB — Leprosy in India: The Road to a Disease-Free Future (October 2025); RPwD Act 2016; Personal Laws (Amendment) Act 2019; NALSA Leprosy Scheme guidelines; PM-JANMAN scheme documentation; Vidhi Centre for Legal Policy — discriminatory leprosy laws analysis; WHO Global Leprosy Report 2023.

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