

**NEEDS ASSESSMENT OF LEPROSY
COLONIES IN SEVEN NLR
SUPPORTED STATES**

YEAR 2023

until
No Leprosy Remains

ACKNOWLEDGEMENT

NLR India acknowledges the support of 129 leprosy colony residents of seven states (Bihar, Delhi, Jharkhand, Rajasthan, Uttarakhand, Uttar Pradesh and West Bengal) in conducting this assessment. The assessment was carried out through more than 100 change agents (adolescents and youth identified by NLR India to work for themselves, their families and community). The change agents were trained as data collectors using a mobile based data collection tool. NLR India thanks them. The information collected by the change agents will be helpful for their own colonies.

Appreciation also goes for the Community Based Rehabilitation Coordinators (CBRCs) of different states working under the guidance of the National Community Based Rehabilitation Coordinator (NCBRC), Head of Programme (HoP) and Manager- Monitoring, Evaluation and Learning. The latter has played the crucial role of defining the methodology, develop the digital tool, guiding the change agents in using the tool, checking data quality, analysis and reporting.



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1. Background

India is having around 750 leprosy colonies ¹. They came up many years back when there was huge stigma and discrimination against the persons affected by leprosy who were unable to live in the general community. As of end 2023, NLR India was working in 150 leprosy colonies across seven states namely Bihar, Delhi, Jharkhand, Rajasthan, Uttarakhand, Uttar Pradesh and West Bengal.

With the pace of development and effective implementation of various national and state policies, and interventions by various civil societies including The International Federation of Anti-Leprosy Associations (ILEP) agencies, the status of leprosy affected persons residing in leprosy colonies have changed over a period of time. It is important to capture the true image of the needs of persons affected by leprosy living in the leprosy colonies.

2. Objective of the needs assessment (NA)

The NA was conducted with the objective “to identify the needs of the persons affected by leprosy living in leprosy colonies.” The information will help NLR India in defining strategic actions for addressing the needs of the leprosy affected and their families residing in the colonies within available resources. The report will also be useful for government, donors and other development partners for supporting survival/ development of the leprosy affected, their children and other family members.

3. Methodology

The NA followed a mixed method approach combining quantitative and qualitative data collection. A tool based on mobile app (KOBO ²) was developed for quantitative data collection. A guide was developed for Focused Group Discussions (FGD). It was attempted to cover all the households of the 150 leprosy colonies. The 150 leprosy colonies had 3,813 households.

3.1 Implementation Plan

The implementation plan was developed and executed in three phases.

Phase-1

- Listing of 150 leprosy colonies
- Development of questionnaire
- Identification of volunteers from leprosy colonies
- Technology set-up (mobile app)
- Training of volunteers for data collection

Phase-2

- Quantitative data collection (door to door)
- Compilation and validation of data

Phase-3

- Qualitative data collection through focus group discussions (FGDs)
- Data interpretation & analysis

¹ Sasakawa India Health Foundation leprosy colony validation report 2019-2020

² KOBO is an open-source mobile application for data collection both online and offline

3.2 Quantitative data collection

Due to operational challenges, a total of 2192 households were interviewed for quantitative survey from 129 leprosy colonies instead of 3,183 households of 150 leprosy colonies from NLR supported seven states (Table 1).

Table 1: State-wise number of colonies covered, household surveyed and FGDs conducted

S.No	State units	Leprosy colonies	Households	FGDs
1	Bihar	22	140	22
2	Delhi	4	104	0
3	Jharkhand	32	416	25
4	Rajasthan	4	77	6
5	Uttar Pradesh	15	365	30
6	Uttarakhand	30	229	18
7	West Bengal	22	861	22
Total		129	2,192	123

The mobile based survey tool was user-friendly mostly with multiple-choice questions. The tool collected the following information: 1] personal details, 2] leprosy diagnosis and treatment, 3] disability, 4] the needs for medical care, disability care and assistive devices, 5] education and livelihood needs, and 6] the documents required to access the government schemes/services.

Engagement of field teams and process for data collection

A team of change agents³ from the leprosy colonies were engaged who were familiar with the language, and the cultural context. Under the direct supervision of NLR India Community Based Rehabilitation Coordinators (CBRCs), the data collection was done in the year 2022.

The change agents were trained on the Kobo Collect mobile app. The training followed a two-step process. First, the CBRCs were trained on installing & using the mobile app and survey tool through online platform. Next the change agents were trained by CBRCs. A written brief guide was also provided to them for using the App for data collection.

The team conducted door-to-door visit and interviewed the heads of the household /family. One single form captured the information for one household. The data was collected offline, and the change agents used to upload the data at the end of the day. The change agents collected informed consent from the heads of households before asking the questions.

³ NLR India has been training some residents in the colonies as change agents who are willing and acting to bring positive changes in own lives, their families and community they live in.

3.3 Qualitative data collection

The plan was to conduct 150 FGDs (one in each colony). Due to operational challenges, we were able to conduct 123 FGDs (Table 1). The FGDs were conducted by the CBRCs assisted by change agents. Each FGD lasted for around one hour. The FGDs were conducted by forming combined groups of male & female residents of the leprosy colonies. The proceedings of the FGDs were audio recorded in local language which were later transcribed and translated into English for data analysis. Informed written consent was obtained from the participants before starting the discussion.

3.4 Challenges in data collection

There were two main operational challenges:

- 1. Logistic and geographical hurdles:** Navigating through the rough terrains was time-consuming and physically demanding, making data collection more difficult. Inadequate transportation, roads & weather conditions like extreme temperatures and heavy rainfall also contributed to the difficulties in gathering data.
- 2. Stigma and reporting issues:** The persons affected were hesitant to share their personal information, including health data, for fear of being judged on various aspects such as employment and education. They were concerned about the group discussions and sharing the issues in groups.

We were able to mitigate these hurdles to an extent by engaging local expertise, careful planning and coordination while working in remote areas and leprosy colonies.

4. Findings

4.1 Profile of respondent households

A total of 2,192 households were interviewed residing in 129 leprosy colonies in 7 NLR supported states of Bihar, Delhi, Jharkhand, Rajasthan, Uttarakhand, Uttar Pradesh and West Bengal. The total population size is 7,024 residing in these colonies (Table 2).

State units	Leprosy colonies covered, n (%)	Total households surveyed, n (%)	Total family Members, n (%)	Average households/ colony	Average family size/ colony
Bihar	22 (17)	140 (6)	751 (11)	6	5
Delhi	4 (3)	104 (5)	379 (5)	26	4
Jharkhand	32 (25)	416 (19)	968 (14)	13	2
Rajasthan	4 (3)	77 (4)	213 (3)	19	3
Uttarakhand	15 (12)	229 (10)	492 (7)	15	2
Uttar Pradesh	30 (23)	365 (17)	1265 (18)	12	3
West Bengal	22 (17)	861 (39)	2956 (42)	39	3
Total	129	2192	7024	17	3

Table 2: State-wise number of households and family members

Gender distribution among households

Out of total 2192 household heads interviewed, 59% are males and 41% are females. One fourth of the total population are children below 18 years of age (Table 3).

Table 3: Gender distribution among households and family members (adults & children)

	Households Heads, n (%)	Adult members, n (%)	Children, n (%)	Total Family members
Male	1296 (59)	2522 (36)	893 (13)	3415
Female	896 (41)	2684 (38)	925 (13)	3609
Total	2192	5206	1818	7024

Adults: 18+ years of age; Children: below 18 years of age

4.2 Availability of bank account, mobile phone and internet

Out of the total of 2192 household heads, 93% (males- 60% and females 40%) had operational bank accounts, 68% had mobile phones (males- 63% and females- 37%). Less than half of the household heads had internet phones (45%). Only 10% of the total households had other internet connections (for laptop and desktops) available with them (Table 4).

Table 4: Status of bank accounts, mobile phones and internet access

	Bank account, n (%)	Mobile phone, n (%)	Phone with internet, n (%)	Wifi access, n (%)
Male	1224 (60)	938 (63)	428 (65)	147 (65)
Female	812 (40)	546 (37)	232 (35)	79 (35)
Total	2036 (93)⁴	1484 (68)⁵	660 (45)⁶	226 (10)⁷

4.3 Leprosy affected: Households and family members

The gender distribution is almost equal among the leprosy affected persons. Out of total affected (2,613), less than 2% are children below 18 years of age (Figure 1).

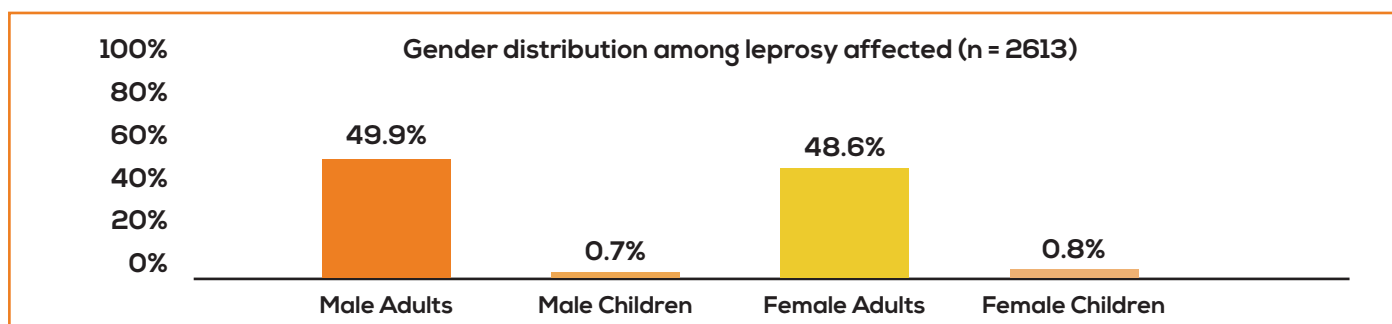


Figure 1: Gender distribution of persons affected with leprosy

4 93% of the households had bank accounts

5 68% of the households had mobile phone

6 45% of the households had phones with internet

7 10% of the households had wifi access

89% of the household heads who were interviewed are leprosy affected (males 58% and females 42%). Out of the total population (7,024), 37% are leprosy affected. The total affected population is highest in Jharkhand (56%) followed by Uttarakhand (52%), Rajasthan (50%), Uttar Pradesh (42%), West Bengal (31%), Bihar (25%) and Delhi (20%) (Table 5).

Table 5: State-wise persons affected with leprosy (HH- household heads; FM- family members)

	A	B	C	D	E	F	G	H	I
	Total households (HH)	Total Population	Affected HH	% affected HHs	Affected FMs	% of affected FMs	Total leprosy affected	% of leprosy affected (out of total population)	% of affected household heads (out of total population)
				$C \div A$		$E \div B$		$G \div B$	$C \div B$
Bihar	140	751	137	98%	49	7%	186	25%	18%
Delhi	104	379	53	51%	21	6%	74	20%	14%
Jharkhand	416	968	407	98%	139	14%	546	56%	42%
Rajasthan	77	213	77	100%	29	14%	106	50%	36%
Uttarakhand	229	492	222	97%	32	7%	254	52%	45%
Uttar Pradesh	365	1265	361	99%	169	13%	530	42%	29%
West Bengal	861	2956	686	80%	231	8%	917	31%	23%
Total	2192	7024	1943	89%	670	10%	2613	37%	28%

However, figure 2 shows that the proportion of affected family members out of affected households is highest in Uttar Pradesh (32%) followed by Delhi (28%), Rajasthan (27%) and Bihar (26%).

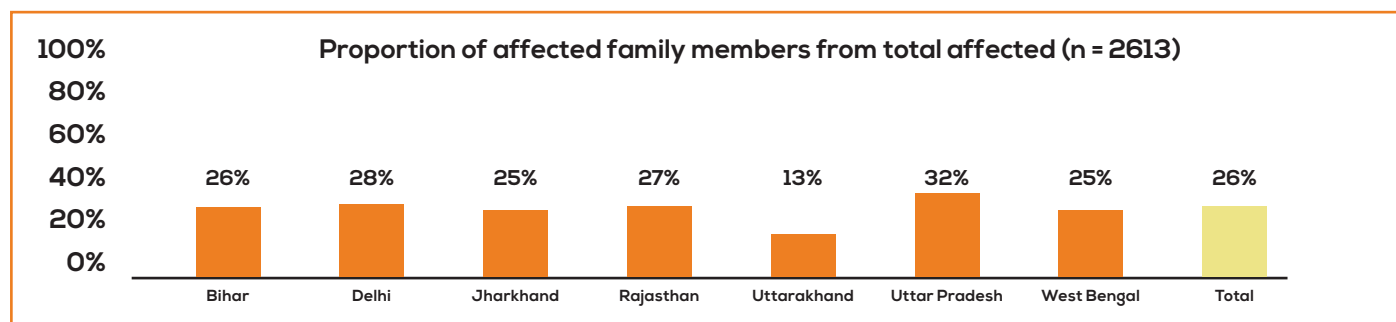


Figure 2: Proportion of leprosy affected family members to affected household heads

4.4 Disability among households and family members

72% of the households have at least one disabled person in the family. Around 28% (1959) of the total population (7,024) have disabilities, 51% are females (Table 6 and Figure 3). 97% of the disabled population have disabilities due to leprosy, only 3% are due to other causes.

Table 6 & figure 4 show the % of disabled among the leprosy affected is highest in Rajasthan (98%) followed by Uttarakhand and Jharkhand (93% each), Uttar Pradesh (89%), Delhi (64%), Bihar (60%) and West Bengal (47%).

As compared to males, the females with disability due to leprosy is highest in Jharkhand (60%) followed by West Bengal (56%), Delhi, Rajasthan & Uttar Pradesh (47% each), Uttarakhand (39%) and Bihar (38%) as shown in the Figure 5.

Table 6: State-wise persons affected with leprosy having disabilities

States	Total Population	Leprosy affected			Persons with Disability (PwDs)			% of PwDs among total population	PwDs due to leprosy			% of disabled among leprosy affected
		M	F	Total	M	F	Total		M	F	Total	
Bihar	751	107	79	186	73	45	118	16%	70	42	112	60%
Delhi	379	37	37	74	25	22	47	12%	25	22	47	64%
Jharkhand	968	217	329	546	202	314	516	53%	201	306	507	93%
Rajasthan	213	56	50	106	56	49	105	49%	55	49	104	98%
Uttarakhand	492	151	103	254	147	95	242	49%	145	92	237	93%
Uttar Pradesh	1265	275	255	530	253	227	480	38%	249	222	471	89%
West Bengal	2956	479	438	917	203	248	451	15%	190	238	428	47%
Total	7024	1322	1291	2613	959	1000	1959	28%	935	971	1906	73%

M- Males; F- Females

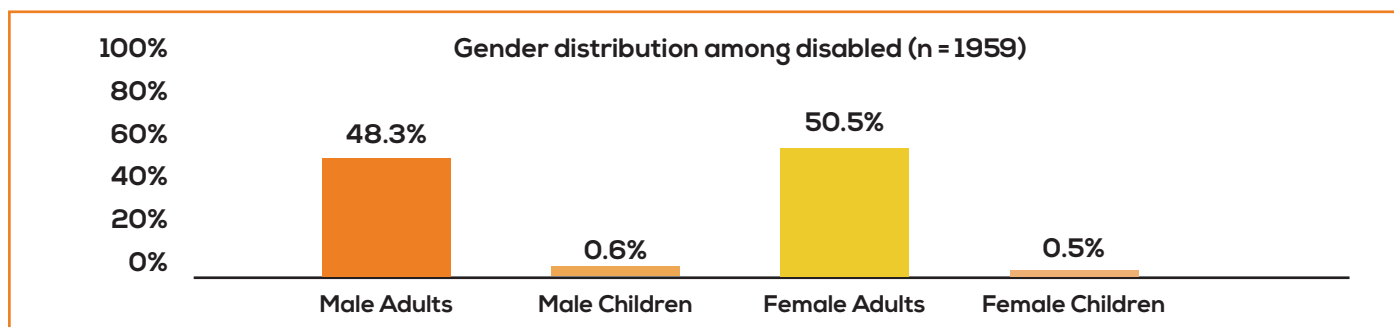


Figure 3: Gender distribution among persons with disability

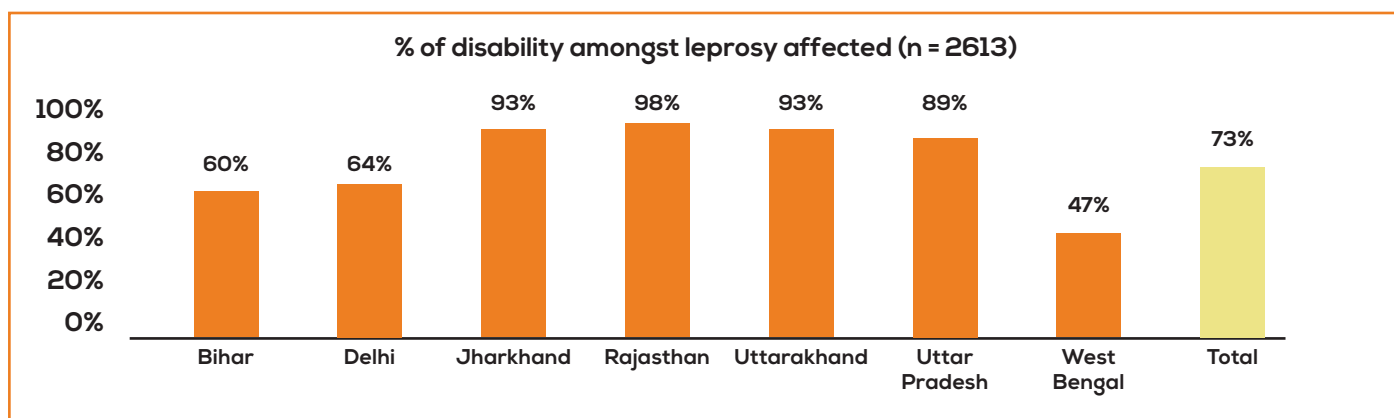


Figure 4: Proportion of persons with disability among population affected with leprosy

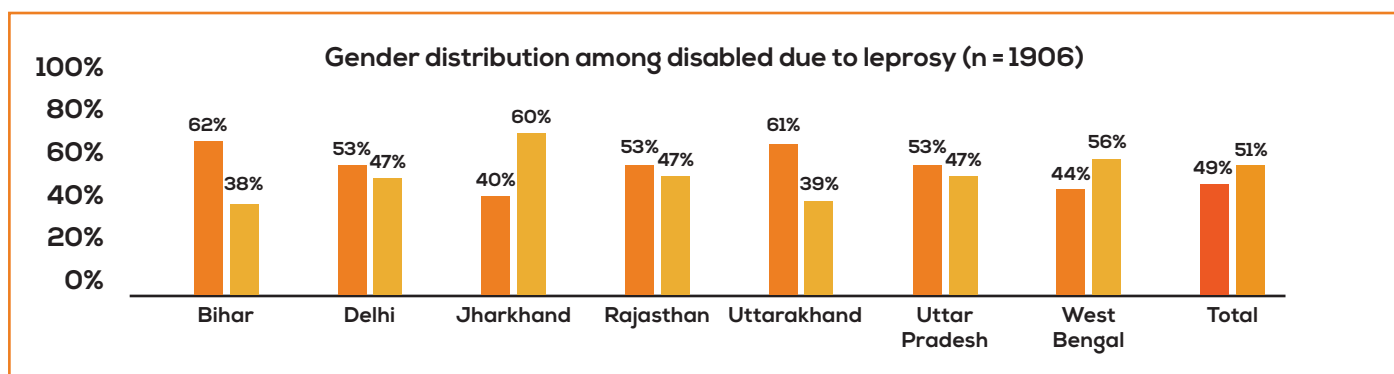


Figure 5: Gender distribution among disabled persons affected with leprosy

4.5 Disability care needs

Out of total 1,959 disabled persons, 77% (1500) of the PWDs need disability care (males 44.5% and females 55.5%) (Figure 6).

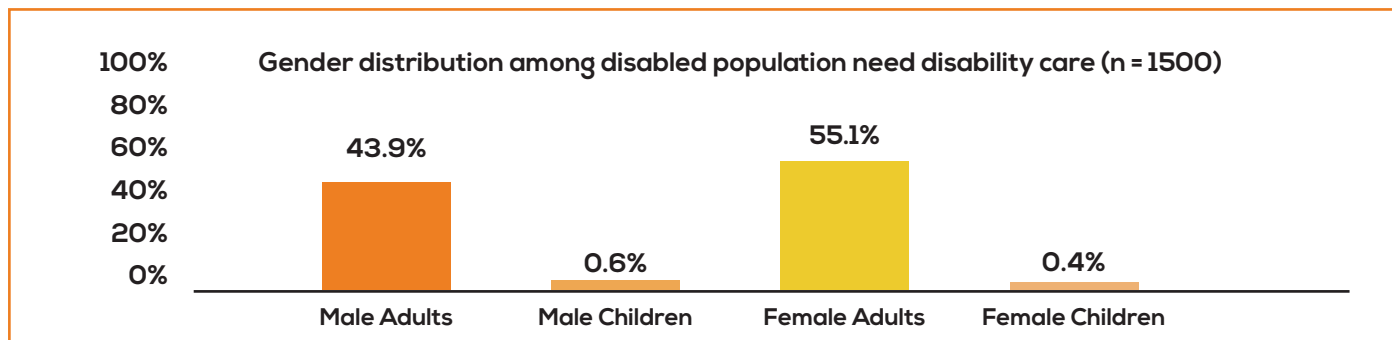


Figure 6: Gender distribution among disabled persons need disability care

Table 7 shows the types of disability care needs namely self-care (86%) followed by specialized wound care (24%), mental health (20%), physiotherapy (10%) and reconstructive surgery (3%).

Through FGDs, it is found that the common items required by persons with disabilities are selfcare kits and dressing kits. In Rajasthan, according to the opinion of the group members, appointing an assistant for dressing of the patients would benefit many disabled persons in the colony for the improvement of their ulcers.

Table 7: Types of disability care needed

	Self-care	Specialized wound care	Physiotherapy	Reconstructive surgery	Mental health	Others
Number of households	1023	287	125	37	235	84
Distribution among households needing disability care	86%	24%	10%	3%	20%	7%

4.6 Assistive device needs

Out of total 1,959 persons with disabilities, 48% (938) need assistive devices (males 49% and females 51%) (Figure 7). Table 8 shows type of assistive device needs namely Micro Cellular Rubber (MCR) footwear (80%), crutches/ baisakhi (46%) and wheelchair/ tricycle (35%).

The percentage of persons with disabilities needing assistive devices is the highest in Uttar Pradesh (78%) followed by Rajasthan (71%), Delhi (64%), West Bengal (41%), Jharkhand (33%), Uttarakhand (32%) and Bihar (25%). (Figure 8). During focus group discussions, these needs were confirmed as the persons with disabilities need assistive devices like wheelchairs, walking stick, crutches and motorized tricycles.

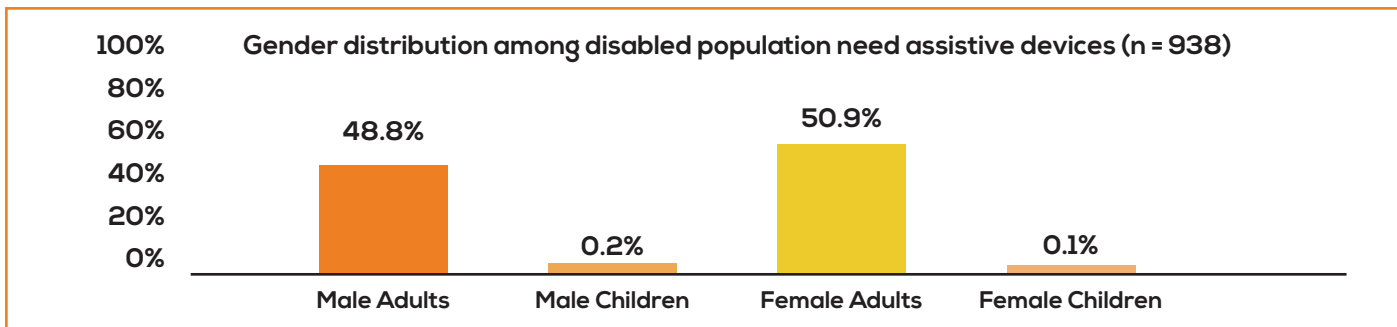


Figure 7: Gender distribution among disabled persons need assistive devices

Table 8: Types of assistive devices needed

	Modified grip	MCR footwear	Goggles	Crutches/ Baisakhi	Wheel chair/ tricycle	Prosthetic equipment	Others
Number of households	122	589	154	337	257	18	30
Distribution among households need assistive devices	17%	80%	21%	46%	35%	2%	4%

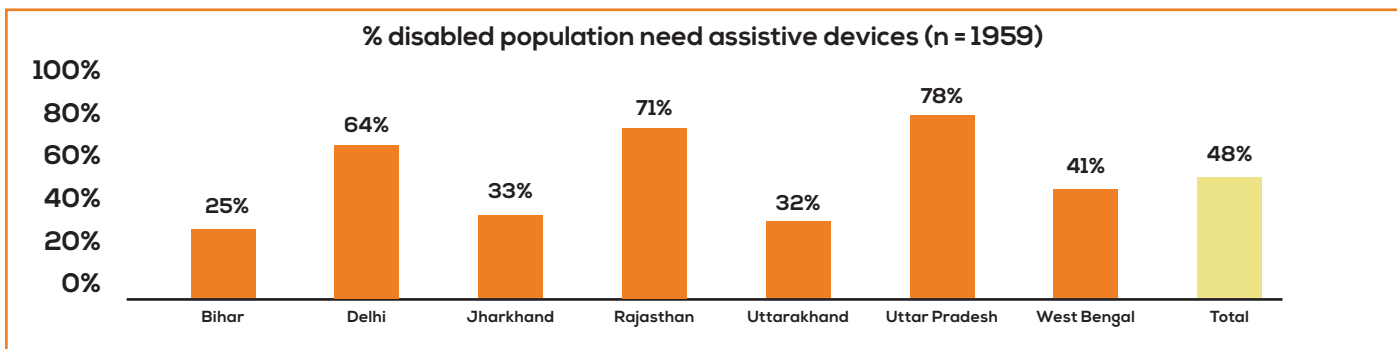


Figure 8: State-wise proportion of disabled persons need assistive devices

4.7 Education needs

24% (1681) of the total population (7024) need education support. including school fees, school dress, school supplies (stationary, books, bag etc), tutors and vocational training; 52% are males and 48% are females (Figure 9).

The maximum need is from Delhi (37%) followed by Bihar (28%), Rajasthan (26%), Uttar Pradesh (25%), Jharkhand (23%), West Bengal (22%) and Uttarakhand (20%). (Figure 10). Through FGDs, it emerged that the youth of Jharkhand colonies are very ambitious and want to enrol for the higher education like graduation, nursing course/ General Nursing & Midwifery (GNM) & Auxiliary Nurse Midwife (ANM) nursing.

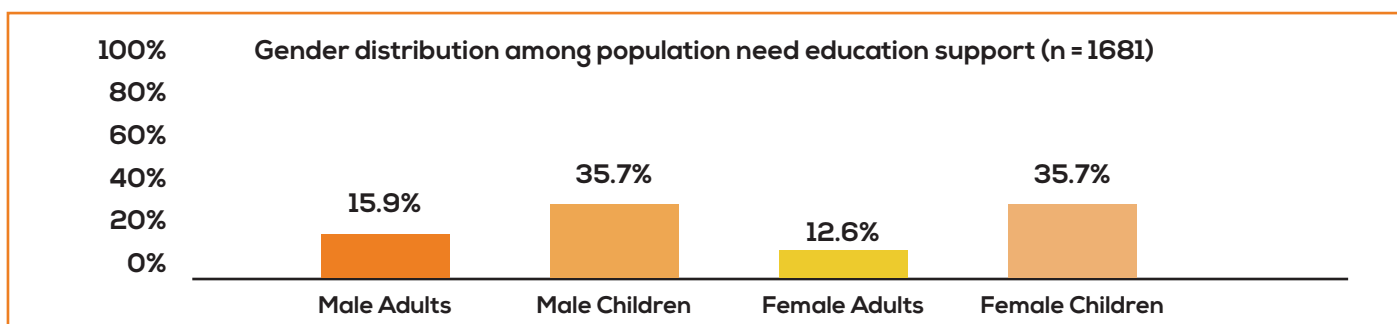


Figure 9: Gender distribution among population need education support

Table 9: Types of education support needed

	School fees	School dress	School supplies; stationary, bag etc	Shoes	Books	Tutors	Vocational Training
Number of households	682	562	622	571	599	479	276
Distribution among households need education support	85%	70%	78%	71%	75%	60%	35%

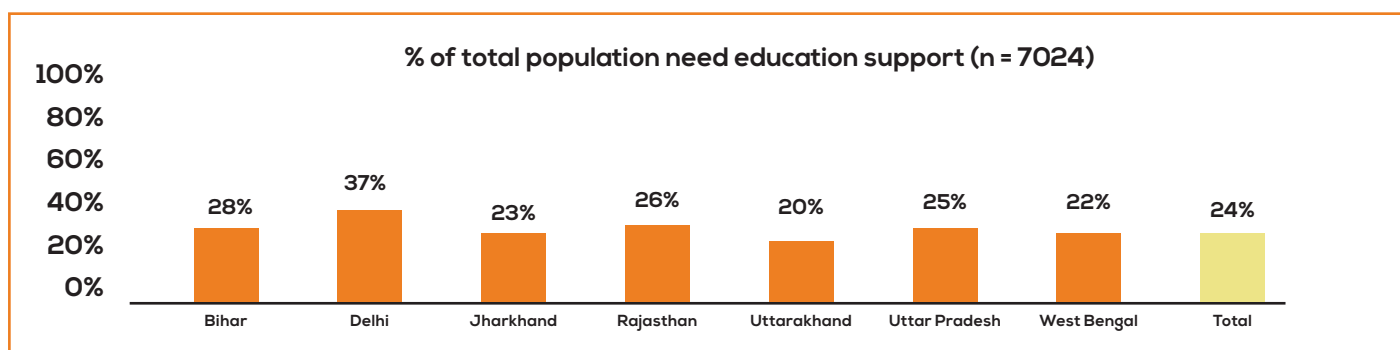


Figure 10: State-wise proportion of population need education support

4.8 Medical care needs

25% (1766) of total population (7,024) need medical care. There is equal distribution between males and females who need medical care. However, few more male children require medical care than female children (Figure 11). The type of major medical care needs are general health care (78%), eye care (28%) and skin care (24%). Around 20% of the households need child health and immunization support for their children in their families (Figure 12).

As shown in Figure 13, the maximum need of medical care is from Rajasthan (55%) followed by Uttarakhand (36%), Uttar Pradesh (36%), West Bengal (26%), Bihar (10%) and Jharkhand (8%).

During the FGDs, the participants have mentioned that elderly and persons affected by leprosy want eye camps, weekly visits by doctors for general health check-up, prescription and medicines and other facilities for severe diseases. There are challenges of water borne diseases in leprosy colonies in West Bengal and the residents have requested for required medical care and treatment.

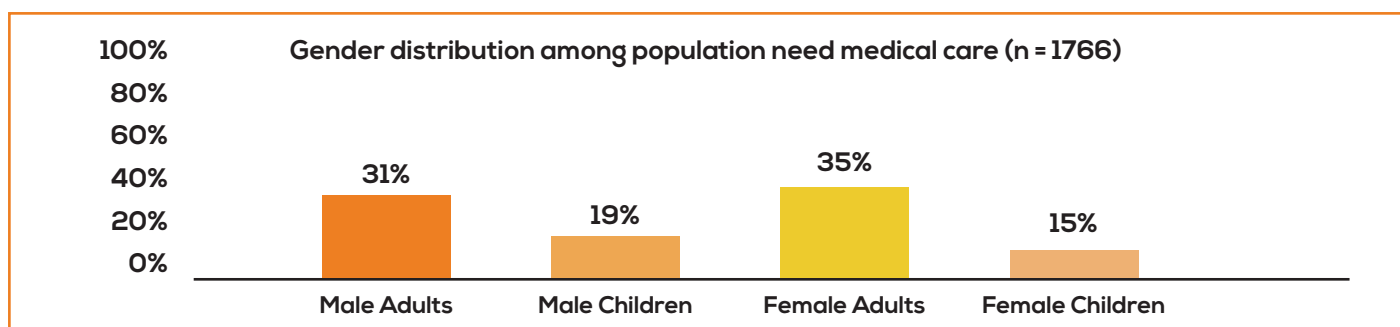


Figure 11: Gender distribution among population need medical care

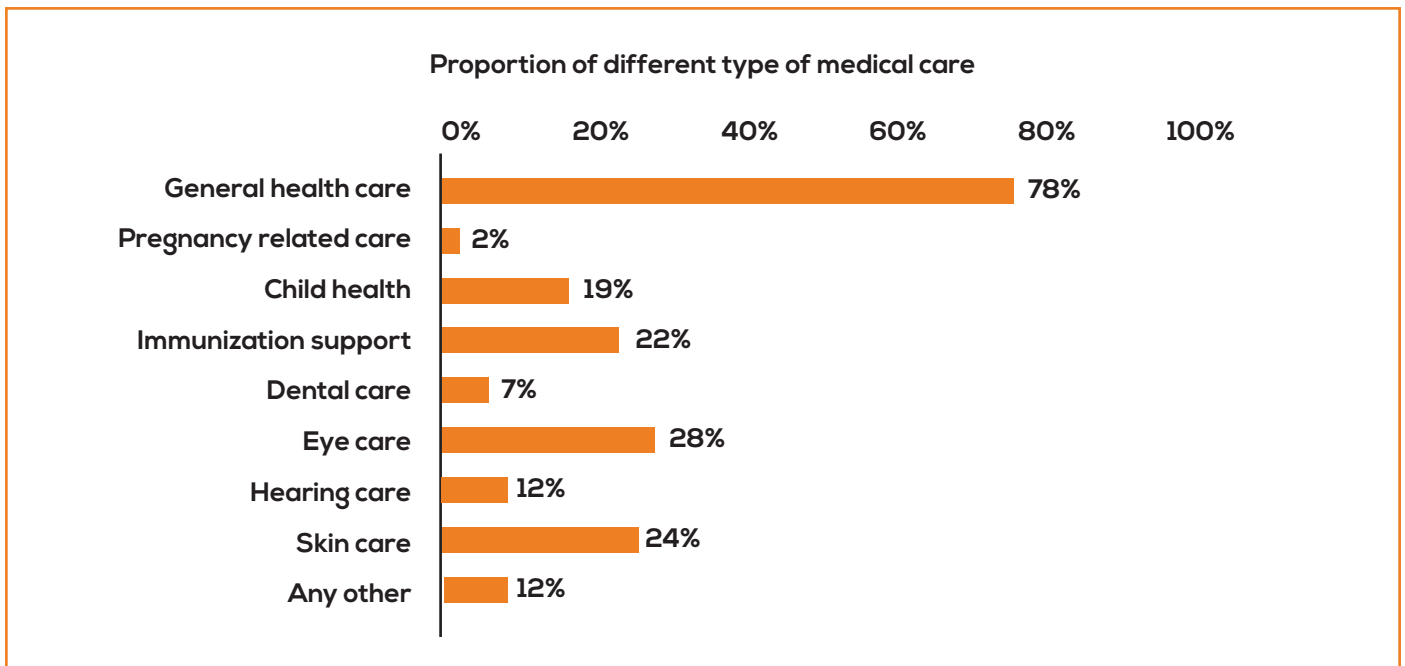


Figure 12: Proportion of different types of medical care needed by the population

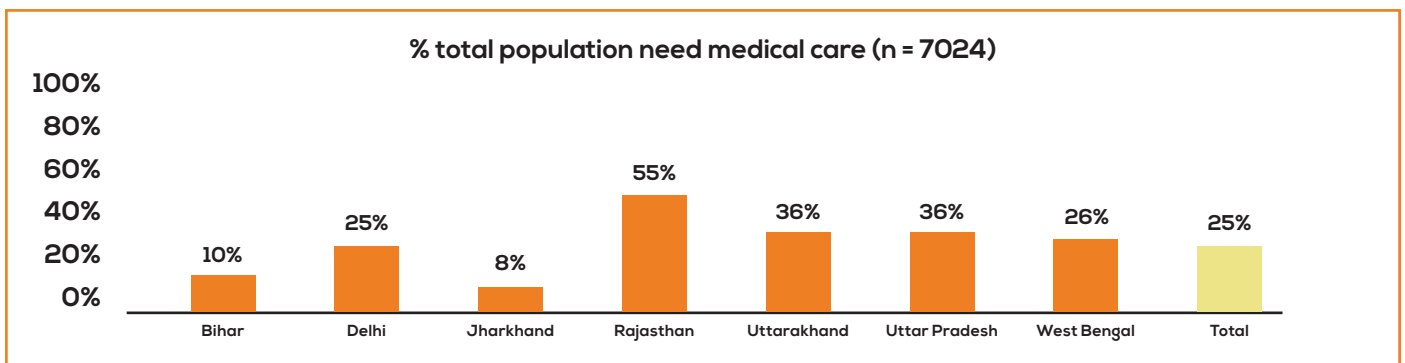


Figure 13: State-wise proportion of population need medical care

4.9 Livelihood needs

28% (1937) of the total population (7,024) need livelihood support.; more than half of them are females (53%).

The different livelihood needs are maximum for financial support for self-employment (62%) followed by employment opportunities (25%), guidance for self-employment (19%) and career counselling (17%) (Table 10). The need of livelihood support is highest in West Bengal (42%) followed by Bihar (35%), Rajasthan (32%), Uttarakhand (16%), Delhi (15%), Jharkhand (15%) and Uttar Pradesh (7%). (Figure 14).

Through FGDs, the participants in Bihar have expressed the need for female empowerment through small business setup and employment opportunities. In Jharkhand, the need of self-employment opportunities arises like small grocery shops, food cart, footpath vending, goat farming and poultry farming.

Table 10: Types of livelihood support needed

	Career counselling	Employment opportunity	Guidance for self-employment	Financial support for self-employment	others
Number of households	182	269	204	652	77
Distribution among households need livelihood support	17%	25%	19%	62%	7%

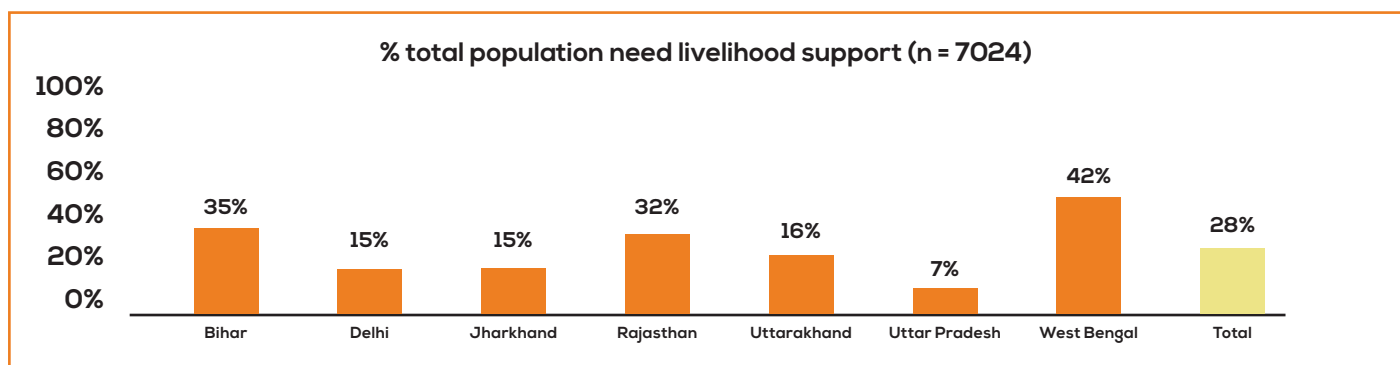


Figure 14: State-wise proportion of population need livelihood support

4.10 Document needs

Out of total household heads (2192), the majority of them have Aadhaar card (94%) followed by voter id (85%) and ration card (75%). Only 10% have Ayushman Bharat and Antodaya card (Table 11).

Figure 15 shows that only 17% (1161) of the total population need support for documents to access govt schemes. The maximum requirement is of Ayushman Bharat card (33%) followed by PAN card (14%). The rest of the documents are Aadhaar card, voter id, disability card, Antodaya card, economically weaker section (EWS) certificate, Below Poverty Line (BPL) card and ration card.

Through FGDs, it was found that the colony people need these documents to avail pension, rail pass, bus pass, access to PM Awas yojana, Mahatma Gandhi National Rural Employment Guarantee Act (MGNREGA) job card and other benefits of various govts schemes available for public.

Table 11: Status of household heads possessing different documents

	Aadhaar card	Voter ID	PAN card	Disability card	Antodaya card	EWS certificate	BPL card	Ration card	Ayushman Bharat card	Others
Numbers	2056	1868	955	1228	213	19	657	1634	230	17
Distribution among households	94%	85%	44%	56%	10%	1%	30%	75%	10%	0.8%

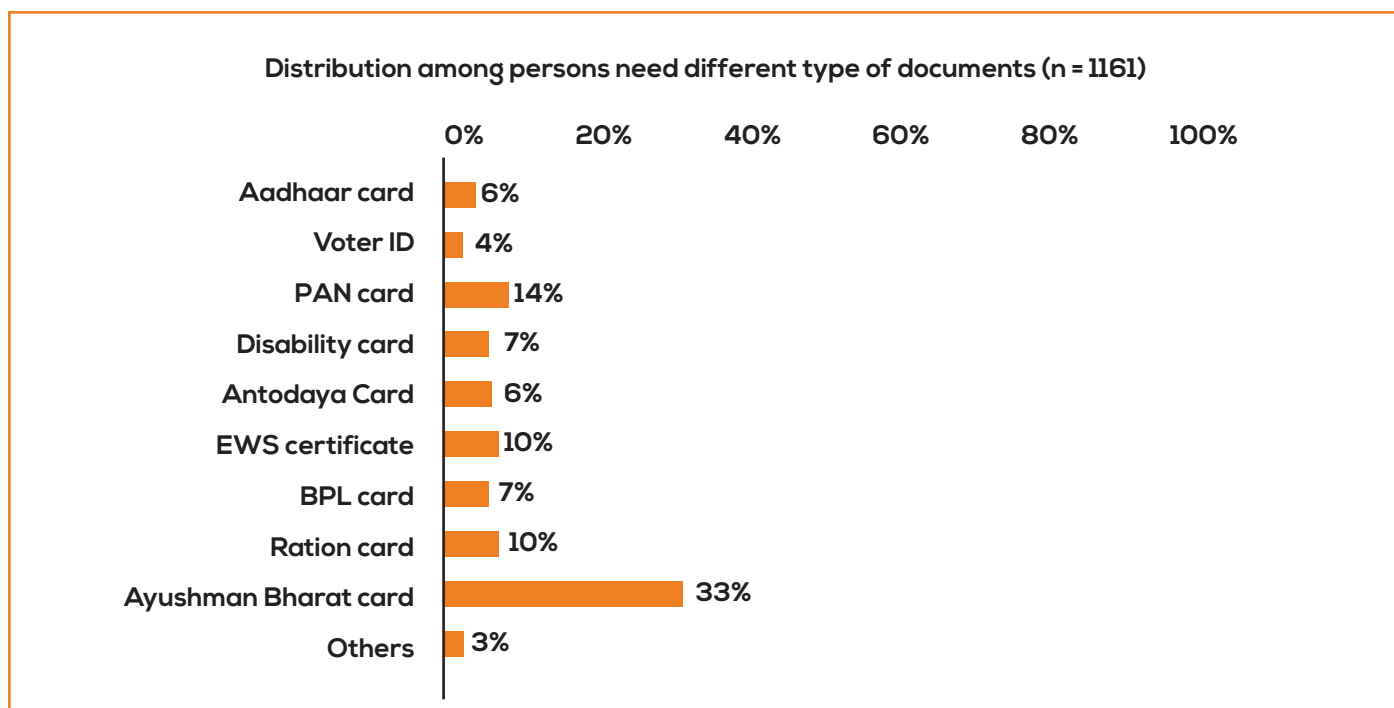


Figure 15: Proportion of different types of documents need

4.11 Infrastructure needs

The majority of the FGD participants have expressed the need for the basic infrastructure like legal electricity connection, drinking water, road, boundary wall, repair or renovation of houses, drainage system, toilets and separate washrooms for males and females. Due to the absence of drainage system in the leprosy colonies, the residents face many problems specially during rainy season.

The participants from Bihar expressed the need for general kitchen for senior citizens, solar lighting in the colony campus, and gas chula. In Jharkhand, Uttar Pradesh and West Bengal, the threat of demolition of the colonies is high, due to extension of national highways and railway tracks.

4.12 Gender related findings

Table 12: Gender related findings

	Parameters	Female	Male
Household heads	Bank accounts	91%	94%
	Mobile phones	61%	72%
	Mobile phones with internet	26%	33%
Documents available with Household heads	Aadhaar card	94%	94%
	Voter ID	86%	84%
	PAN card	39%	47%
	Disability card	59%	54%
	Antodaya card	11%	9%
	EWS certificate	1%	1%
	BPL card	30%	30%
	Ration card	75%	74%
Ayushman Bharat card	14%	8%	

	Parameters	Female	Male
Leprosy affected & disability	Leprosy affected household heads	90%	88%
	Total leprosy affected	36%	39%
	Total PWDs	28%	28%
	PWDs due to leprosy	97%	97%
Type of needs	Disability care	83%	70%
	Assistive Device	48%	48%
	Education	22%	25%
	Medical care	21%	30%
	Livelihood	29%	27%

It is pleasing to see there is gender equity in terms of possessing mobile phone, internet, different documents for accessing services and the needs for different needs except disability care where the need of females is higher. In fact, more women are in possession of Ayushman Bharat card and have expressed their willingness to earn.

4.13 Other Findings

The FGDs from Bihar revealed the mutual cooperation among colony members is lacking with some people left lonely and helpless. In Uttar Pradesh, the participants have expressed the non leprosy affected residents of the colonies use the major portion of the donations meant for the affected people. The FGD participants have also expressed that persons affected with leprosy feel discriminated when they go out of the colonies for begging or any other work. The conflict between the colonies and communities is a major reason for non-development of the colony. There is a need to bring harmony with the community.

5. Summary and Conclusion

This study has played a pivotal role in highlighting the needs and challenges faced by 7,024 (males- 49% & females-51%) residents of 129 leprosy colonies in 7 NLR India supported states of Bihar, Delhi, Jharkhand, Rajasthan, Uttarakhand, Uttar Pradesh and West Bengal. The average family size per household is 3.

Table 13: Key findings

Key findings		Numbers	%
Population	Total	7024	
	Adults	5206	74%
	Children	1818	26%
Household heads	Total	2192	
	Bank accounts	2036	93%
	Mobile phones	1484	68%
	Phones with internet	660	30%
	Wifi access	226	10%
Leprosy affected and disabilities	Leprosy affected	2613	37%
	Persons with disability	1959	28%
	PwDs due to leprosy	1906	73%

Key findings		Numbers	%
Type of needs	Disability care	1500	77%
	Assistive Device	938	48%
	Education	1681	24%
	Medical care	1766	25%
	Livelihood	1937	28%
	Document	1161	17%

- Besides adults, there are good number of children who require support.
- Significant number of households have bank accounts.
- Good number of households have mobile phones and almost half of them have internet access.
- Almost one third of the leprosy colony residents have disability.
- Almost 80% of the persons with disabilities require disability care including self-care, specialized wound care, mental health, physiotherapy and reconstructive surgery.
- Around half of the persons with disabilities need assistive devices namely MCR footwear, crutches/ baisakhi and wheelchair/ tricycle to help them with their daily activities.
- Nearly one-fourth of the total population need education support like school fees, school dress, school supplies (stationary, books, bag etc), tutors and vocational training. The youth of Jharkhand colonies are very ambitious and aspire to pursue higher education, including graduation, nursing courses such as GNM and ANM.
- One-fourth of the total population need medical care like general health care, eye care and skin care. In FGDs, the participants highlighted that the elderly and persons affected with leprosy need eye camps, regular visits by doctors for general health check-ups, prescriptions and medications.
- Almost one third of the residents require support for livelihood such as financial assistance for self-employment like setting up small grocery shops, food carts, footpath vending, goat farming, and poultry farming. They also emphasized the importance of having sufficient employment opportunities, receiving guidance for self-employment and career counselling services.
- More than 80% of the residents have the essential documents to access different schemes.
- Most colonies require basic amenities such as safe drinking water, legal electrical connections, roads, boundary walls, drainage systems, and separate toilets for men and women.
- During the data collection, some of the respondents were hesitant to share information. This may be due to self-stigma or concern of confidentiality. Some residents expressed they feel discriminated when they go out of the colonies for begging or any other work.
- Some respondents expressed that other persons who are not affected by leprosy use the major portion of the donations meant for the affected people.

Most of the residents (both male & female) have the required documents to access different government services and schemes. However, they still require lot of support ranging from care for their disabilities, other health problems, education and livelihood. There are also a large number of basic needs to be addressed like water and sanitation along with discrimination by the general community.



until
No Leprosy Remains



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