NLR INDIA

25 years SILVER JUBILEE CELEBRATION

LEPROSY LIVES MATTER

Evaluation Report

Evaluation of NLR India Projects, 2024

until
No Leprosy Remains

Table of Contents

List of Tables & Figure

List of Acronyms

ADL:	Activities of Daily Living
ANCDR:	Annual New Case Detection Rate
ASHA:	Accredited Social Health Activist
BDC:	Block Development Committee
BPS:	Basic Psychological Support
CAPI:	Computer Assisted Personal Interview
CBO:	Community Based Organization
CSC:	Combined Selfcare
DID:	Disability Inclusive Development
DLO:	District Leprosy Officer
FGD:	Focus Group Discussion
G2D:	Grade 2 Disability
GHC:	General Healthcare
GIS:	Geographical Information System
HBSC:	Homebased Selfcare
IADL:	Instrumental Activities of Daily Living
ICT:	Information & Communication Technology
IDI:	In-Depth Interview
IRB:	Institutional Review Board
LF:	Lymphatic Filariasis
LPO:	Leprosy People Organizations
LSE:	Life Skills & Education
MDT:	Multi-Drug Therapy
NGO:	Non-Government Organization
NLEP:	National Leprosy Eradication Programme
NTD:	Neglected Tropical Diseases
NUHM:	National Urban Health Mission
PEP:	Post-Exposure Prophylaxis
PHC:	Primary Health Centre
PRI:	Panchayati Raj Institution
RPWD:	Rights of Persons with Disabilities
SC:	Selfcare
SCC:	Selfcare at Colonies
SCPHC:	Selfcare at PHC
SDR:	Single Dose Rifampicin
SLO:	State Leprosy Officer
SRH:	Sexual & Reproductive Health
ULEP:	Urban Leprosy Programme
UPHC:	Urban Primary Health Centres
WHO:	World Health Organization

Acknowledgements

NLR India extends its gratitude to the Technical Advisory Committee (TAC) members for their invaluable guidance and expertise throughout the evaluation:

1. Dr. Sudarshan Mandal (Chair, TAC): Senior Chief Medical Officer, National Centre for Vector Borne Disease Control (NCVBDC) & Former Deputy Director General (Leprosy), Central Leprosy Division, Ministry of Health & Family Welfare, Government of India
2. Dr. Manas Kundu: Director, Regional Leprosy Training and Research Institute (RTLRI), Gouripur, Bankura, West Bengal
3. Dr. Zakir Hussain: Professor, Economics Department, Presidency University, Kolkata
4. Dr. Vijay Laxmi Godara: State Leprosy Officer, Rajasthan
5. Dr. Rashmi Shukla: National Professional Officer (Leprosy), WHO Country Office, New Delhi
6. Ms. Maya Ranvare: President, Association of People Affected by Leprosy (APAL)
7. Mr. Rajni Kant Singh: State Coordinator, Lepra India
8. Dr. Lalit Kant: Vice Chairperson, Governing Board, NLR India
9. Ms. Heleen Broekkamp: Senior Programme Officer, NRL International, Amsterdam
10. Dr. Ashok Agarwal, Chief Executive Officer, NLR India

Dr. Pravin Kumar, National Head of Project of NLR India played the key role in coordination with the TAC and Athena Infonomics, the Research Agency which conducted the external evaluation following a research methodology. He also made sure all support was provided to the field team for data collection.

The study data was collected from different states namely Bihar, Jharkhand, Rajasthan, Uttar Pradesh and West Bengal. NLR India acknowledges the support provided by the different government officials and the frontline workers who supported in collecting the study data. Some of them were also interviewed as study respondents.

NLR India thanks Athena Infonomics, the Research Agency who conducted the study as per the study protocol. The Athena study team functioned under the guidance of Dr. Rajesh Khanna (Project Director) and Dr. Pratap Manglani (Leprosy Expert Consultant). The diligent efforts of Mr. Abison Paul (Principal Consultant), Mr. Manav Sharma (Consultant & Project Manager), and Mr. Anish Panjiyar (Data Analyst) played a pivotal role in the success of this evaluation.

NLR India recognizes the crucial role played by its state teams including State Programme Leads and Community-Based Rehabilitation Coordinators. Their availability and valuable contributions during the data collection process enriched the depth and quality of this assessment. Amit Jain, Manager – Monitoring, Evaluation & Learning, NLR India reviewed the data analysis done by the research agency.

Our sincere appreciation goes to all the study participants at various levels who participated in interviews and discussions, offering critical insights that shaped the findings of this report. Their willingness to share perspectives and experiences has been instrumental in providing a comprehensive understanding of the projects under evaluation. Special thanks to NLR India Change Agents who played an important role in facilitating the colony and community participants.

To everyone who played a role, large or small, in the realization of this evaluation, we express our deepest gratitude. Your collaboration has been essential in advancing our understanding of leprosy care and contributing to ongoing efforts for a leprosy-free society.

Executive Summary

NLR India embarked on a comprehensive evaluation to assess the impact and effectiveness of its projects aimed at combating leprosy and related disabilities across various states in India. The different projects including four models of disability care and others evolved over many years. All the projects have been implemented in close collaboration with government and other stakeholders. This evaluation sought to provide valuable insights for future strategies and advocacy efforts, ensuring alignment with the evolving needs of the leprosy-affected population.

Leprosy persists as a public health challenge in India, despite advancements in treatment. Challenges include delayed diagnosis, stigma, inadequate healthcare infrastructure, and fragmented efforts. NLR India's projects address these challenges through innovative approaches, community engagement, and advocacy efforts. These initiatives aimed to reduce the burden of leprosy, empower affected individuals, and foster community inclusion.

The evaluation employed a mixed-method research design, incorporating both qualitative and quantitative methods to gather comprehensive learning from the following projects:

A] Disability care projects

1. Homebased Self-Care (HBSC) implemented in West Bengal
2. Selfcare at Colonies (SCC) implemented in Bihar, Jharkhand, Rajasthan and Uttar Pradesh (UP)
3. Selfcare at Primary Health Center (SPHC) implemented in Bihar, Rajasthan and UP
4. Combined Self-Care (CSC) Camps implemented in Bihar, Jharkhand and UP

B] Disability Inclusive Development (DID) implemented in Bihar, Jharkhand and UP

C] Urban Leprosy Programme (ULP) implemented in West Bengal

D] Call Centre VIKALP) project implemented in Jharkhand, Rajasthan and Uttarakhand

The projects 1-4 represent the four different models of disability care, the selfcare at colonies being the oldest (starting in 2008). The role of NLR India in HBSC and ULP has been providing the concept to the government and assisting in roll out through project design, training, monitoring and mentoring. The HBSC and ULP are being implemented in West Bengal. The disability care projects were implemented with the following objectives: 1] To enable leprosy (and lymphatic filariasis) affected persons to take care of their disabilities through self-care, and 2] To capacitate the government staff in implementing selfcare intervention. The DID project (since 2016) was implemented with the objective "to empower the community-based peoples' institutions to such an extent that they are able to stand before the duty bearers for their rights and entitlements, in a collective manner". The objective of the ULP (since 2020) was "to improve delivery of leprosy services in urban areas of West Bengal". The call centre (Vikalp) project (since 2021) is being implemented with the objectives: 1] Improve drug adherence to Multi Drug Therapy (MDT) for leprosy, 2] Promote practice of self-care among the new cases with disabilities, and 3] Promote preventive chemotherapy among the household contacts of the new cases.

The evaluation was conducted with the following **objectives**: 1] Assess impact on target groups (self-care, disability empowerment, drug adherence, leprosy services in urban areas), 2] Evaluate acceptability by the government health system and the community, 3] Assess ease of implementation and address implementation challenges, 4] Evaluate behaviour change among beneficiaries, community, and government health staff, 5] Analyse cost-effectiveness of different models/approaches, 6] Assess future implementation needs and

modifications, 7] Depict key outcomes and success stories through outcome harvesting, and 8] Provide recommendations for integration, replication, and sustainability.

The study protocol was reviewed and approved by the Sigma Institutional Review Board (IRB).

The quantitative data was collected from 718 respondents. The qualitative data was collected through 49 in-depth interviews (IDI) and 05 focus group discussions (FGD). The respondents were spread across five states namely Bihar, Jharkhand, Rajasthan, Uttar Pradesh (UP) and West Bengal.

The study data was collected in around 3 weeks during December 2023 and January 2024.

Findings from the Survey:

A] The Disability Care projects

Homebased Self-Care Project

The Homebased Self-Care Project has revolutionized disability care by providing support directly to disabled leprosy patients in their homes, fostering independence and improving quality of life. Through tailored interventions and community partnerships, the project has witnessed notable improvements in patient outcomes and caregiver support.

The project's success lies in its personalized approach, delivering home-based support services that address the unique needs of each individual. This approach has resulted in positive outcomes, including increased satisfaction levels among beneficiaries and improved accessibility to essential support services. 73.8% of beneficiaries reported improvement in their life & well-being as a result of the project's interventions.

To sustain momentum and expand the project's impact, recommendations include scaling up home-based support services, strengthening community partnerships, and customizing support services to meet individual needs. Leveraging technology for remote support, advocating for policy reforms to prioritize home-based care, and establishing peer support networks would further enhance the project's impact, ensuring equitable access to care and support for disabled leprosy patients in home settings.

Selfcare at Colonies

The Selfcare at Colonies project has played a pivotal role in improving self-care practices among residents of leprosy colonies, fostering a culture of proactive health management and community empowerment. Through targeted interventions, including training sessions and peer support networks, the project has witnessed a notable improvement in self-care practices, with 49.4% of residents adopting and implementing self-care methods to enhance their health and well-being. One of the project's key successes lies in the positive changes observed in community dynamics and well-being, with 83.5% of residents reporting improved health outcomes and enhanced social cohesion within the colonies. Testimonials and observations affirm the project's effectiveness in promoting self-care practices and nurturing a supportive community environment.

To sustain and expand the project's impact, recommendations include sustaining momentum by expanding outreach efforts, strengthening community partnerships, and tailoring support services to meet the specific needs of residents. Leveraging technology for remote support, advocating for policy reforms to prioritize community-based interventions, and establishing peer support networks would further enhance the project's impact, ensuring sustainable improvements in health and well-being within leprosy colonies.

Combined Self-Care Camps

The Combined Self-Care Camps project has emerged as a cornerstone in empowering individuals affected by both leprosy and Lymphatic Filariasis (LF) to manage their conditions effectively. Through multifaceted interventions, including training camps and psychological support, the project has fostered a culture of self-care and community engagement.

The project's success is evidenced by high attendance rates, positive satisfaction levels, and improvements in self-care practices among beneficiaries. Majority of attendees reported a improvement in their ability to manage their conditions through self-care methods, showcasing the tangible impact of the project's interventions. Tailored support services, community engagement strategies, and partnerships with healthcare providers have contributed to positive outcomes, empowering individuals to integrate proactive health practices into their daily lives. The project's holistic approach has led to 61.9% of beneficiaries engaging in regular self-care practices, highlighting the sustainability of positive health behaviours.

Moving forward, the project recommends integrating combined self-care modules into existing healthcare systems, enhancing community partnerships, and advocating for policy changes to prioritize integrated care approaches. Emphasizing capacity building for healthcare providers, leveraging technology for remote support, and fostering peer support networks would further strengthen the project's impact, promoting holistic well-being among individuals affected by leprosy and LF.

Selfcare at PHC

The Selfcare at PHC project has been instrumental in empowering individuals affected by leprosy to take charge of their health through self-care practices delivered at Primary Health Centres (PHCs). The project's impact is evident in the improvement in participants' knowledge about leprosy, with 76.3% reporting a notable enhancement. This increase in knowledge has translated into tangible outcomes, with 87.3% of beneficiaries experiencing improved life & well-being.

One of the project's key strengths lies in its high participation rates, with over 91% of beneficiaries actively engaging in self-care training camps. Moreover, the project has successfully fostered a culture of regular self-care practices, embraced by 76.3% of beneficiaries, indicating the successful translation of acquired knowledge into daily routines. The project's holistic approach is further underscored by over half of the beneficiaries accessing a range of schemes related to disability management and self-care methods. While the project has demonstrated success, challenges such as barriers in the distribution of assistive devices and accessing reconstruction surgeries have been identified. These challenges highlight the need for seamless service delivery and targeted interventions to ensure comprehensive support for individuals affected by leprosy.

To sustain and enhance the project's impact, recommendations include integrating self-care practices into existing healthcare systems, enhancing capacity building for healthcare providers, and advocating for policy support to institutionalize self-care interventions. Community engagement, continuous monitoring, and knowledge exchange should be prioritized to foster independence and holistic well-being among individuals affected by leprosy.

The four different selfcare models were compared across six different parameters namely 1] Improvement in leprosy awareness, 2] improvement in selfcare knowledge, 3] regular practice of selfcare, 4] positive impact on life and well-being, 5] activities of daily living (ADL) 6] and instrumental activities of daily living (IADL). The selfcare at PHC (SCPHC) ranked first followed by combined selfcare (CSC), selfcare at leprosy colonies (SCC) and home-based selfcare (HBSC). However, each of them has their unique advantages.

B] Disability Inclusive Development

The Disability Inclusive Development (DID) project, implemented across Bihar, Jharkhand, and Uttar Pradesh, has demonstrated impact in enhancing the well-being and empowerment of individuals affected by leprosy. Through a multi-faceted approach focusing on self-care practices, economic empowerment, and social inclusion, the project has achieved remarkable outcomes.

Economic empowerment initiatives under the DID project have resulted in tangible improvements in livelihood opportunities, with 73% of beneficiaries reporting increased income or livelihoods. Through access to financial education and government schemes, beneficiaries have demonstrated enhanced financial management skills (86.9% saving a portion of their income regularly), laying the foundation for long-term economic stability.

The project has fostered greater social Inclusion and community participation among individuals affected by leprosy. Increased engagement in community activities (28.8%) and a surge in social support from the community (84.4%) highlight improved social acceptance and integration. Moreover, 76.3% of beneficiaries have actively participated in community development initiatives, underscoring their growing sense of ownership and agency. The successful establishment of disability-inclusive development in model districts serves as a testament to the project's efficacy. Through targeted vocational training, awareness campaigns, and community engagement initiatives, the project has demonstrated the feasibility and effectiveness of disability-inclusive development approaches. Testimonials and stories of beneficiaries achieving independence further validate the transformative outcomes of empowerment initiatives. The DID project has also seen notable improvement in self-care practices among beneficiaries, with 67.5% reporting regular engagement in self-care activities. Access to assistive devices and awareness campaigns has contributed to improved mobility and physical well-being, reflected in beneficiaries'' positive outlook on their overall life and well-being (86.3%).

In conclusion, the DID project has made strides in empowering individuals affected by leprosy, promoting disability-inclusive development, and fostering sustainable change across communities. By leveraging its success and building on key learnings, the project is poised to continue making a meaningful impact in the lives of its beneficiaries and setting a precedent for future disability-inclusive initiatives.

C] Urban Leprosy Programme

The Urban Leprosy Programme, spearheaded by NLR India in collaboration with government health systems, has emerged as a transformative initiative in addressing the multifaceted challenges of leprosy in urban West Bengal. Through a comprehensive approach focusing on enhancing health services, empowering individuals, and fostering community engagement, the programme has achieved notable milestones and tangible impacts across various domains.

The programme has strengthened leprosy services in urban areas, with a notable percentage of new cases diagnosed by Urban Primary Health Centre (UPHC) Medical Officers. This outcome reflects enhanced access to timely diagnosis and treatment, leading to improved health outcomes for affected individuals. A notable percentage of beneficiaries actively engaged in self-care training, demonstrating increased knowledge and skills in managing their condition. By promoting self-reliance and autonomy, the programme empowers individuals to take charge of their health and well-being.

The programme has fostered increased social support and acceptance among beneficiaries, as evidenced by improved community engagement and reported impact on social events. By breaking down social barriers and promoting inclusion, the programme creates supportive environments where individuals affected by leprosy can thrive.

D] Call Centre Project: VIKALP

The Vikalp Project, also known as the Call Centre Project, represents a pioneering initiative in leprosy management leveraging Information & Communication Technology (ICT) to address the complex challenges posed by the disease. The project operates through a call centre based in Jaipur, Rajasthan. Based on the line list of patients on treatment received from the district leprosy office, the counsellors call the patients every two weeks. The patients also call as per need. Each month and as per need, the call centre reports to the district leprosy office and the follow-up support to be provided through the general health care staff. Information on patients suspected to have leprosy reaction, is conveyed to the district leprosy office at the earliest.

Collaboration between the call centre and District Leprosy Staff (DLS) emerged as a cornerstone o' the project's success, with 100% of respondents reporting collaboration for case management and follow-ups. High levels of satisfaction with the collaborative approach highlight its effectiveness in facilitating timely communication, information exchange, and support, thereby enhancing treatment outcomes and reducing the burden of disease. Survey findings indicate the respondents received 96.8%, 100%, and 64.5% counselling support for continuation of MDT, selfcare and preventive chemotherapy to family respectively. 'The project's achievements are further supported by positive feedback from beneficiaries, with high satisfaction levels reported regarding the call centre services, including information provision, counselling, and support. Additionally, the project's proactive engagement and proactive stance in addressing leprosy-related challenges underscore its commitment to ensuring ongoing support and communication throughout the treatment cycle. While the project has demonstrated progress in achieving its objectives, there remain opportunities for further improvement and expansion. Recommendations for future action include enhancing integration of services, replicating successful approaches in other regions with high leprosy burden, and ensuring the long-term sustainability of project interventions through capacity-building, community involvement, and advocacy efforts.

In conclusion, the Vikalp Project stands as a testament to the transformative potential of ICT in addressing complex health challenges. By empowering individuals, fostering collaboration, and leveraging innovative approaches, the project not only contributes to improving treatment outcomes and reducing the burden of leprosy but also serves as a model for holistic and patient-centred healthcare delivery in resource-constrained settings.

Key Results Achieved

Table 1: Key Results Achieved: Combined

Project	Key Results	Supporting Evidence
Homebased Selfcare	***Improved Life & Well-being***	• 73.8% of the project population have had very positive to positive experience of overall life & well-being.
	Empowerment Through Knowledge	• 100% of the project beneficiaries reported an increase in both leprosy and selfcare methods knowledge.
Selfcare at Colonies	***Enhanced Community Participation in Self-Care***	• 71.5% of beneficiaries heard about the intervention through a community event/meeting. • 100% of the respondents reported increase in the community awareness regarding leprosy out of which 38.6% reported a great change.
	Strengthened Social Support Networks	• 59.5% go to community events at least occasionally, with an overall 79.7% of respondents being involved in social events. • 81.6% of respondents experienced increased support from community towards their disability.
Selfcare at PHC	***Increased Adherence to Self-Care Practices***	• 99.2% of beneficiaries responded with practicing selfcare methods, of which 76.3% practice selfcare regularly.
	Improved Health Literacy and Empowerment	• 74.7% of beneficiaries reported a positive impact of the assistive devices provided. • 97.5% of the survey population reported improved knowledge on selfcare methods (of which 65.3% reported a great change) • Similar trends are observed in Leprosy Knowledge with 98.3% of population responding with an affirmative response.
Combined Selfcare	***Enhanced Self-Efficacy and Independence***	• 97% of the population was reported to be in the "Independent" zone in ADL Scale.
	Strengthened Social Support Networks	• 55.4% of the population feel confident in participating in community events. • 88.1% of beneficiaries visit community events or meetings at least occasionally. • Qualitative inputs suggested the respondents experienced increased social support from community members post implementation of the project.
Disability Inclusive Development	***Economic Empowerment and Livelihood Improvement***	• 71.9% of beneficiaries reported an increase in income or improvement in livelihoods. Beneficiaries (85.6%) saved a portion of their income regularly, demonstrating enhanced financial management skills and stability. • Access to government schemes and services, such as disability pensions (73.1%) provided crucial financial support to beneficiaries.
	Social Inclusion and Community Participation	• Beneficiaries (84.4%) noted an increase in social support from the community, highlighting improved social inclusion and acceptance. • 76.3% of beneficiaries have become actively involved in community development initiatives or projects, showcasing their growing sense of ownership and agency. • 40% of beneficiaries reporting either frequent or always involvement in community activities since participating in the project.
	Enhanced Self-Care Practices and Well-being	• Self-care practices improved with 67.5% reporting regular care disabilities. Beneficiaries (85.6%) expressed a very positive or positive outlook on their overall life and well-being, reflecting a tangible shift towards optimism and resilience

Project	Key Results	Supporting Evidence
Urban Leprosy Programme	***Improved Health Services and Self-Care***	• 31.7% of new leprosy cases diagnosed by UPHC Medical Officers showcase rollout of leprosy services by urban primary health centers in urban areas. • 80.5% of beneficiaries reported an increase in knowledge about leprosy, reflecting improved awareness and understanding of the disease. • 56.1% of beneficiaries referred by frontline health workers to UPHCs, indicating active engagement with healthcare services
	Community Engagement and Social Support	• 24.4% of beneficiaries reported an increase in social support from their community, highlighting improved acceptance and integration. • 48.8% of beneficiaries reported slight impact on social events or community activities, showcasing a moderate level of community engagement. • 34.1% of beneficiaries reported occasionally participating in community events, demonstrating some level of involvement in community activities.
Call Centre Vikalp	***Empowerment through knowledge on drug adherence, Self-Care, and preventive chemotherapy***	• 96.8% of respondents reported improvement in drug adherence to MDT. • 100% of respondents gained knowledge on self-care practices. • 58.1% of respondents reported practicing self-care methods regularly, with an additional 41.9% practicing them occasionally. • 64.5% of respondents understood the importance of preventive chemotherapy to their family members.
	Strengthening Collaboration for Comprehensive Care	• 100% of respondents reported collaboration between the call centre and District Leprosy Staff (DLS) for case management and follow-ups. • Survey findings indicate high levels of satisfaction with the collaborative approach, with 77.4% of respondents considering it very helpful and an additional 22.6% considering it helpful for receiving follow-up services. • All respondents received regular calls from the call centre, highlighting effective communication and coordination between project components.

Study Limitation

The major limitation of the study was the absence of baseline. The changes identified are based on the changes experienced by the beneficiaries, and substantiated by the government health care providers and NLR India staff.

About NLR India & Purpose of Evaluation

NLR India is a non-profit, non-religious, non-governmental organization working with the vision "Creation of an inclusive society free from leprosy, allied skin NTDs and related disabilities". It was registered as a Trust in 1999. The organization works in close collaboration with the government at the centre and states. From 2024, NLR India plans to work in eight states namely Assam, Bihar, Delhi, Jharkhand, Madhya Pradesh, Rajasthan, Uttar Pradesh & West Bengal. The organization's pilot interventions/ research etc. are aimed towards bringing innovations for making the government programmes more effective and efficient. NLR India is an Alliance member of NLR International, Netherlands. NLR International was founded to realise a world without leprosy. NLR International has NGOs in Brazil, India, Indonesia, Mozambique, and Nepal. It is also a member of International Federation of Anti-Leprosy Associations (ILEP)- a consortium of international NGOs working to eliminate leprosy and other NTDs.

Over the last 25 years (since 1999), NLR India has made the following contributions:

- Piloted feasibility of leprosy preventive chemotherapy, now being implemented as a national programme.
- Rolled out successfully the enhanced chemoprophylaxis -PEP++ stop transmission of leprosy, a global clinical trial.
- Developed models of leprosy self-care, now being scaled up by different state governments.
- Model on community-based Disability Inclusive Development.
- Development of children of leprosy affected as Change Agents.
- Life Skills Education and Sexual Reproductive Health guidance in leprosy colonies.
- The first ever helpline for leprosy.
- Developed Basic Psychological Support for persons with disability due to leprosy and lymphatic filariasis (BPS-N) guide, and provided Proof of Concept demonstrating effectiveness of Peer Supporter led BPS-N intervention.

Purpose of evaluation

The above contributions have been part of different projects/ models/ interventions which have evolved over the years. NLR India will like to evaluate all the important projects for drawing learnings and advocate for government and other stakeholders for replication. This will also help NLR India identify priorities for its future in line with the national strategic plan for interruption of leprosy transmission, its capacity and resources.

Summary of the evaluated projects

A. Disability Care projects

1. Self-care camps in leprosy colonies. These were started in 2008, and the last camps were organized in 2018 in Jharkhand. These camps were organized in 85 colonies of four states (Bihar, Delhi, Jharkhand and Uttar Pradesh).
2. Self-care camps at PHCs. These were started in 2010, the persons affected by leprosy are invited through ASHAs at the Primary Health Centre (PHC) to attend the training camps. These camps are for the leprosy affected living in villages and communities. Bihar and Jharkhand state governments have adopted these models and rolled them out across all districts with NLR India technical assistance.

3. Combined Selfcare camps (CSC). This model was started in 2015, under this both the persons affected by leprosy and Lymphatic Filariasis (LF) are provided training on self- care at the PHC camps.
4. Homebased selfcare (HBSC). This was started in West Bengal in 2019 to deliver the selfcare services at the doorsteps of disabled persons. NLR India proposed to the Government of West Bengal the idea of HBSC, which the government accepted. Under this, ASHA workers and other frontline workers visit the houses of the persons with disability due to leprosy every month and provide them the disability care.

During the camps and the HBSC, the affected persons are trained on self-care practices and provided necessary logistic supplies like tubs, ointments, oil, soap, assistive devices, microcellular rubber (MCR) footwear etc. Self-care groups are also formed for relationship building, mutual support, and sustainability. The camps also serve as hand-on training for the general health care staff by NLR India for them to conduct the camps by themselves.

The key objectives of the self-care projects are:

- To enable leprosy (and lymphatic filariasis) affected persons to take care of their disabilities through self-care.
- To capacitate the government staff in implementing selfcare intervention.

B. Disability-Inclusive Development (DID)

Disability and discrimination may lead to loss of livelihood and persons affected are trapped in a vicious cycle of poverty and destitution. They are excluded in society and have much less social interaction. NLR India developed a novel approach to address the social and rehabilitation related issues of the persons affected by leprosy and disabilities. The approach called "Disability Inclusive Development (DID), is being implemented in Aurangabad district of Bihar since 2016. It focused on empowering the persons with disability (PWD) through a community-based development approach and making the villages disable friendly. In Aurangabad there are around 74000 PWDs out of which around 25% are due to leprosy. The PWDs have formed SHGs, block development committees, organization of PWDs (OPDs) etc. The project ensures that PWDs have equal access to development programmes and services. The same model is now being implemented through providing technical assistance in 10 districts of three states (Bihar, Jharkhand and Uttar Pradesh).

The overall objective of the project is to empower the community-based peoples' institutions to such an extent that they are able to stand before the duty bearers for their rights and entitlements, in a collective manner. The sub objectives are:

1. The persons with disabilities collectivize in community-based institutes like self-help groups, Organization of Persons with Disability (OPD) and Block Development Committee (BDC).
2. The PWDs community-based institutes define their agenda for empowerment.
3. PWDs and their families are able to access benefits of government schemes.

C. Urban NLEP in West Bengal

The services for leprosy in urban areas has been a challenge in India. NLR India proposed to the state government of West Bengal for involvement of the National Urban Health Mission (NUHM) infrastructure for delivery of leprosy services in urban areas. The medical officers and field staff under NUHM were trained and services were gradually started in 127 urban areas of West Bengal covering a population of over 30 million. This intervention

started in 2020. At present field workers refer suspects from field to urban primary health centers (UPHC) for diagnosis and start of treatment. Patients directly attending hospitals are referred back to UPHCs for treatment. This intervention has been successful in implementation of Leprosy Postexposure Prophylaxis (LPEP) in urban areas which was earlier neglected. The effect of this intervention has been visible as the treatment completion rate is over 90% (as of March 2023) compared to 60% in the end of 2020) and disability rate among newly detected cases is around 10% (as of end March 2023 compared to 15% in 2020).

The overall objective of the project was to improve delivery of leprosy services in urban areas of West Bengal.

The sub-objectives are:

1. The Urban Primary Health Centres (UPHCs) are enabled to provide leprosy services.
2. Increase in detection and treatment of new cases of leprosy.
3. Increase in administration of Single Dose Rifampicin for Post-Exposure Prophylaxis (SDR-PEP).
4. Decrease in grade 2 disability (G2D) among new cases of leprosy.

D. Call centre – VIKALP

NLR India designed an information and communication technology (ICT) based approach for case management and follow-up of new leprosy cases, which would improve the drug adherence by the patient; support the monitoring and follow-up for improvements, compliance, any side effects, and counselling of patients on signs and symptoms and other related issues. For this, a call centre was established at Jaipur (Rajasthan) under the project called VIKALP (Validation of integrated call centre-based approach for Leprosy). The dedicated counsellors who after receiving the line-list from selected districts, call the patients fortnightly till completion of their treatment. During the call, the counsellors explain about the disease, its nature, myths and facts and encourages him/her to complete treatment within stipulated time as per prescription. They also counsel them on selfcare and prevention of leprosy. This pilot was implemented in Alwar, Jaipur, Ranchi, Haridwar, Dehradun, and Pali (3 states: Jharkhand, Rajasthan and Uttarakhand). After its start in May 2021, until April 2023, the call centre has been able to follow 218 cases.

The objectives of the project are:

1. Improve drug adherence to Multi Drug Therapy (MDT) for leprosy.
2. Promote practice of self-care among the new cases with disabilities.
3. Promote preventive chemotherapy among the household contacts of the new cases.

Evaluation Methodology

Evaluation Objectives

This evaluation aimed to not only provide valuable insights and lessons learned but also serve as a basis for advocating the replication of successful initiatives by the government and other stakeholders.

- Assess impact on target groups (self-care, disability empowerment, drug adherence, leprosy services in urban areas).
- Evaluate acceptability by the government health system and the community.
- Assess ease of implementation and address implementation challenges.
- Evaluate behaviour change among beneficiaries, community, and government health staff.
- Assess future implementation needs and modifications.
- Depict key outcomes and success stories through outcome harvesting.
- Provide recommendations for integration, replication, and sustainability.

Methodology Overview

Research Design

The study incorporated a holistic **mixed method research design** comprised of both qualitative and quantitative methods. The research design with the proposed research methods and proposed target groups is illustrated below.

Table 2: Research Design

Mixed Method Research Design	
Quantitative	Qualitative
▪ Structured Interviews ▪ Semi-Structured	▪ In-Depth Interviews ▪ FGDs

The selfcare project beneficiaries also responded to ADL and IADL tools.

ADL & IADL Assessment

The activities of daily living are classified into basic ADLs and Instrumental Activities of Daily Living (IADLs). The basic ADLs (BADL) or physical ADLs are those skills required to manage one's basic physical needs, including personal hygiene or grooming, dressing, toileting, transferring or ambulating, and eating. The Instrumental Activities of Daily Living (IADLs) include more complex activities related to the ability to live independently in the community. This would include activities such as e.g., managing finances and medications, food preparation, housekeeping, laundry.

Table 3: ADL & IADL Thematic Areas

ADL Themes	IADL Themes
Personal Hygiene	Cooking
Dressing	Cleaning & Housekeeping
Feeding	Managing Finances
Mobility	Transportation
Toileting	Communication
Continence	

Measurement of ADLs

Defining the extent of loss of ADL and IADL is important to help define and ensure appropriate care support. Several checklists have been developed by various entities. Although there is some consensus among what ADLs should be included, there exists significant variability on how these questionnaires ask about ADL functions. The most frequently used checklists are the Katz Index of Independence in Activities of Daily Living[1] and the Lawton Instrumental Activities of Daily Living (IADL) Scale[2]. The Katz scale assesses the basic activities of daily living but does not assess more advanced activities of daily living. The Katz ADL scale is sensitive to changes in declining health status, but its limitations include the limited in its ability to measure small elements of change seen in the rehabilitation of older adults. However, it is very useful in creating a common language about patient function for healthcare providers involved in the overall care and discharge planning.

The Lawton Instrumental Activities of Daily Living (IADL) Scale is used to evaluate independent living skills (Lawton & Brody, 1969). The instrument is most useful for identifying how a person is functioning and identifying improvement or deterioration over time. The limitations of this scale are that it is a self-administered test rather than the actual demonstration of the functional task. This may lead either to over-estimation or under-estimation of the ability to perform the activity.

Each prompt contained three-point Likert scale-based responses (0: Unable, 1: Partially able, 2: Able). The responses were added, and the results were segregated among the following categories of scores.

- 0%-30%: Severe Dependence
- 31%-50%: Moderate Dependence
- 51%-70%: Mild Dependence
- 71%+: Independence

1. Katz, S., Ford, A. B., Moskowitz, R. W., Jackson, B. A., Jaffe, M. W., & Habicht, W. (1963). Studies of illness in the aged. The index of ADL: A standardized measure of biological and psychosocial function. Journal of the American Medical Association, 185(12), 914-919.
2. Lawton, M. P., & Brody, E. M. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. The Gerontologist, 9(3), 179-186.

Methodology

Sample size calculation

Quantitative:

A statistically significant quantitative sample size was calculated for the study. Based on the information available in hand, sample size was computed by using the following formula:

$$N = Z^2pq/d^2$$

Where,

N= the desired sample size (when population size is more than 10,000)

Z= the standard deviation, set at 1.96 in correspondence with 95% confidence level

p= estimated proportion of the population that presents the leprosy characteristics

q= 1.0-p

d= degree of accuracy desired, set at 0.1

Taking 10% non-response rate into account, the following minimum samples per state were obtained for the relevant states:

Table 4: Minimum State-wise Sample Size

S. No.	State	Prevalence per 10000	Sample	10% Buffer *	Total (N)
1	Bihar	0.58	20.9	2.09	23
2	Jharkhand	0.86	30.19	3.019	33
3	Rajasthan	0.1	3.8	0.38	4
4	Uttar Pradesh	0.33	12.25	1.225	13
5	West Bengal	0.46	16.8	1.68	18

* For non-response

The N in table 3 indicates the minimum sample size for each project per state.

An extrapolation factor of ~2.5 was utilized to capture quantitative data from a variety of respondents, accurately capturing the experiences and impact perceived by beneficiaries across the seven projects implemented in five states. This gave us a total sample size of 700 beneficiaries for the study. The sample size is appropriate for state level and combined interpretations.

Qualitative:

In the qualitative approach, the team conducted key in-depth interviews (IDI) with government officials, community leaders and project stakeholders. An interview schedule with relevant guidelines was developed in line with the objectives of the assessment.

Sampling Strategy

Stakeholders were covered from each of the projects and subsequent sub-projects for a comprehensive evaluation. The sample was collected from all the states and leprosy colonies, after a review of the secondary literature along with the discussion with technical advisory committee (TAC), the following procedures were finalized:

- Selection of districts: Two districts were selected based on the coverage and number of beneficiaries. One high performing and one low performing district was selected to create insights after comparisons between variant geographies, for a total of 2 district per state.
- Selection of Blocks/Leprosy Colonies: Two blocks were selected based on the coverage and number of beneficiaries. One high performing and one low performing block was selected to understand the differences in between various geographies, for a total of 2 blocks per district.
- Selection of villages/urban areas: Villages or urban areas were selected based on the maximum number of beneficiaries in the given geography. During our interaction with block level staff at PHCs, a listing of beneficiaries was acquired to finalise the list of villages to be covered.
- Selection of Beneficiaries: Random selection of beneficiaries was done to ensure representation of groups for structured interviews with beneficiaries. Qualitative beneficiaries were identified in due consultation with NLR India project team. Considerations to include cross gendered responses were kept in mind.

Inclusion Criteria

The survey protocol included specific inclusion criterion respective of each stakeholder part of the study to ensure relevance and quality of insights. The table below details the criteria utilized to identify stakeholders.

Table 5: Inclusion Criteria

S. No.	Level of Interview	Type of Interview	Category of Respondent	Inclusion Criteria
1	Leprosy Colonies	Quantitative	Beneficiaries	Individual should preferably be a beneficiary of the leprosy project for at least 2 years
2	Health Centre	Qualitative	Frontline Workers	The frontline worker must be involved in the dissemination of services in the leprosy colonies
3	Health Centre	Qualitative	Community Members	Community members from the project geographies - representatives from Community-Based Organizations (CBOs), PRI, Peer Groups, and SHGs who have been involved in the project
4	District	Qualitative	Block and District Level Functionaries	Block and District level government officials involved in the leprosy service delivery in the community
5	District	Qualitative	Programme Managers and Trainers	NLR India staff embedded in implementation of respective leprosy programme
6	State	Qualitative	NLR India Staff and Consultants	NLR India Staff involved in the monitoring and management of the overall programme

Survey Implementation

Training of Enumerators

A two-day virtual training workshop was organized for the team of data collectors and supervisors on the 15th and 16th of December 2023. A substantial part of the training focused on manoeuvring the tablet application for data collection, hands-on training with the tablets that would be used for the data collection. The training was conducted through presentations, and group discussions, and followed by a session of mock interviews to familiarize the enumerators with the questionnaire flow.

Ethical Protocols

The survey protocol and evaluation tools were reviewed, amended based on the feedback received and approved by the Sigma Institutional Review Board (IRB). The team engaged and received orientation from NLR India Focal Persons on the sensitivities required to interact with persons affected by leprosy and related diseases. The study also ensured that all the universally accepted principles of research, viz. respect for the confidentiality of identity of respondents, respect for their right to refuse an interview, end the conversation at any stage or refuse to share a particular detail, respect for privacy and personal dignity of respondents, etc. were duly observed. Not only during the data collection but also while processing and coding the data, these ethical principles were adhered to. The data team assured the anonymity and confidentiality of participants' data and assured the visual data is protected and used for agreed purposes only.

Primary Data Collection

The field survey for the study commenced from the 18th of December 2023. The primary data collection was conducted in each evaluation state in parallel to maximise productivity and accommodate the state specific variations in terms of authorization, institution visits, and scheduling. The quantitative data was collected in an android tablet-based Computer Assisted Personal Interview (CAPI). The data collection and validation process concluded on the 2nd of January 2024.

Achieved Sample Size

The envisaged sample size was completed in the selected geographies of the projects. Any drop out in respondents was compensated by collecting additional samples from other relevant geographies to achieve both the state and programme specific envisaged samples.

Table 6: Achieved Quantitative Sample

S. No.	State	Programme	Envisaged Sample	Sample Achieved
1	Bihar	SCC At Colonies	57	27
		SCC AT PHCs	53	59
		Combined SCCs	53	58
		Disability Inclusive Development	53	55
2	Jharkhand	SCC At Colonies	75	100
		Combined SCCs	75	75
		Disability Inclusive Development	75	75
3	Uttar Pradesh	SCC At Colonies	30	31
		SCC AT PHCs	27	27
		Combined SCCs	30	35
		Disability Inclusive Development	30	30
4	Rajasthan	SCC AT PHCs	32	32
		Call Center Vikalp	32	31
5	West Bengal	Homebased Selfcare	41	42
		Urban Leprosy	41	41
Total			**700**	**718**

In addition to the aforementioned quantitative sample, a total of 54 qualitative interviews/ discussions were conducted as in-depth interviews (49) with frontline workers (23), community members (8), government officials (4), project team (14), and focus groups (5) with beneficiaries to complement and accentuate the quantitative findings.

Thematic Structure of Presented Findings

NLR India envisions a world where leprosy is eradicated, and its associated challenges are replaced by inclusivity. The organization's mission is encapsulated by the ambitious pursuit of achieving ***"three zeros": zero transmission, zero disability, and zero exclusion/stigma in leprosy***. The projects adopt the following central themes to guide the implementation:

1. **Empowerment through Self-Care:** The common thread across projects, promoting the idea that individuals affected by leprosy can actively participate in their own care. These initiatives, fueled by the belief in self, focus on fostering independence, reducing disability, and enhancing overall well-being.
2. **Holistic Well-Being Community Involvement and Inclusivity:** Recognizing that the impact of leprosy extends beyond physical health, projects focus improving overall well-being, social participation, and quality of life. Leveraging community resources and collaboration to ensure that interventions are culturally sensitive, sustainable, and inclusive, contributing to zero exclusion/stigma.
3. **Collaboration & Advocacy:** Pragmatic approach to enhance leprosy services through collaboration with local stakeholders as well as the government systems, the projects emphasize the power of coordinated efforts in combating leprosy. The narrative here revolves around collaboration, strategic resource utilization, and the pursuit of NLR India's overarching vision.

This report employs a comprehensive lens, intricately examining the key themes that underpin each project. Through a meticulous assessment, the findings aim to shed light on the transformative power of NLR India's endeavors. In presenting the findings through these three key lenses, the report seeks to provide a comprehensive narrative that not only captures the essence of each project but also synthesizes the collective impact on individuals, communities, and the broader landscape of leprosy care.

1. **Project-Specific Insights:** The first lens through which the findings unfold is Project-Specific Insights. This section delves into the nuanced experiences of respondents within each project. By focusing on the help received and understanding the intricacies of individual experiences, this approach aims to provide a vivid portrayal of the initiatives' impact on the ground. It unveils the stories of those directly touched by NLR India's projects, offering a deep and personal understanding of the practical implications and real-world efficacy of each endeavor.
2. **Knowledge Improvement:** The second lens brings into focus the realm of Knowledge Improvement. At the heart of this assessment lies the exploration of improvements in leprosy and self-care knowledge and practices. Here, the report scrutinizes the effectiveness of educational components embedded within the projects. By unraveling the knowledge gained and the tangible changes in self-care practices, this lens illuminates the educational success stories, highlighting the pivotal role of knowledge enhancement in the broader context of leprosy control and disability prevention.

3. **Impact Assessment:** The third and final lens of the report's assessment is Impact Assessment. This multifaceted evaluation is divided into two parts: Activities of Daily Living (ADL) & Instrumental Activities of Daily Living (IADL) and Holistic Improvements. The former provides a granular understanding of personal improvements, offering insights into the day-to-day impact on the lives of individuals. The latter, encapsulating life & well-being, social participation, and quality of life, aligns seamlessly with NLR India's overarching vision. This section aims to uncover the holistic transformation brought about by the projects, emphasizing their alignment with the organization's grand vision.

Respondent Information for Quantitative Survey

The quantitative data was collected from beneficiaries of different projects including persons affected by leprosy and lymphatic filariasis, and other persons primarily with locomotor disabilities. The age distribution findings underscore the significance of considering demographic nuances in tailoring interventions. While older individuals predominate, there are notable variations across states and projects, emphasizing the need for targeted strategies to address the diverse age groups effectively. The analysis of age distribution among respondents reveals compelling insights into the demographic composition across states and specific projects undertaken by NLR India.

State-wise Overview:

- **Bihar:** Dominated by the 45+ age group (61.8%), Bihar exhibits a higher concentration of older respondents compared to other states. Notably, Bihar has minimal representation in the <= 17 years age group (1.0%).
- **Jharkhand:** Jharkhand demonstrates a diverse age distribution, with a major percentage in the 45+ age group (58.0%) and a substantial representation in the 26 - 35 years age group (11.2%).
- **Uttar Pradesh:** Uttar Pradesh displays a varied age profile, with a notable percentage in the 36 - 45 years age group (30.9%) and a lower representation in the <= 17 years age group (0.0%).
- **Rajasthan:** Rajasthan exhibits a higher percentage of respondents in the 36 - 45 years age group (33.3%), showcasing a concentration of individuals in the middle-age range.
- **West Bengal:** West Bengal stands out with a comparatively (between states) higher proportion of respondents in the <= 17 years age group (4.8%), indicating a comparatively younger demography.

Figure 1: Age Category (In Percentage): Project Specific (N=718)

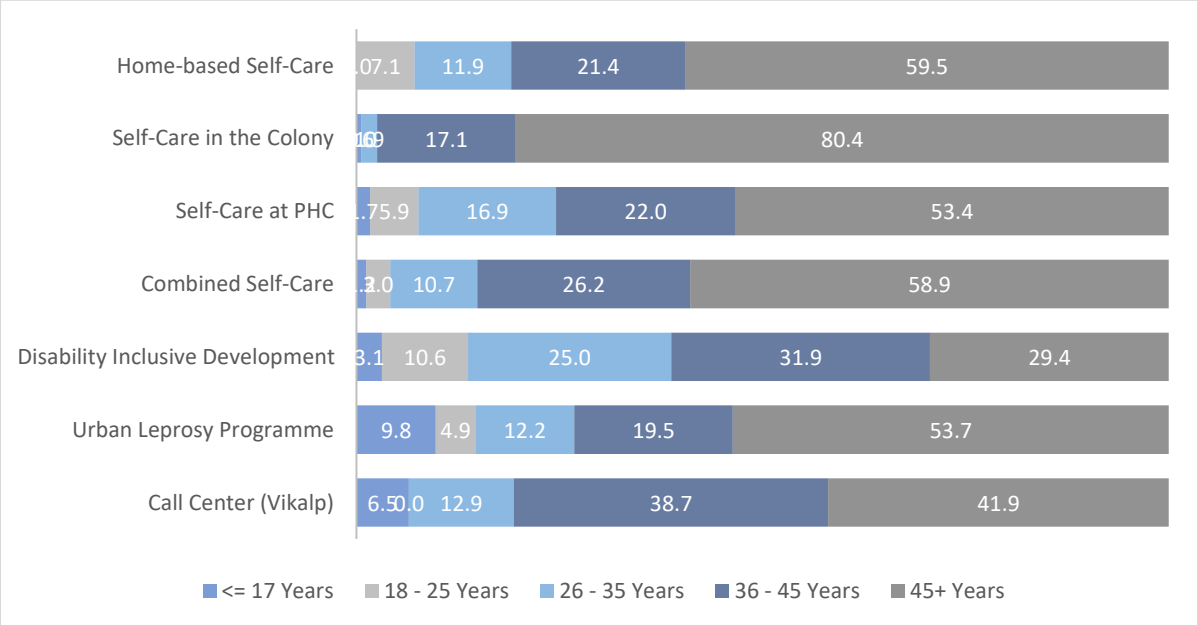
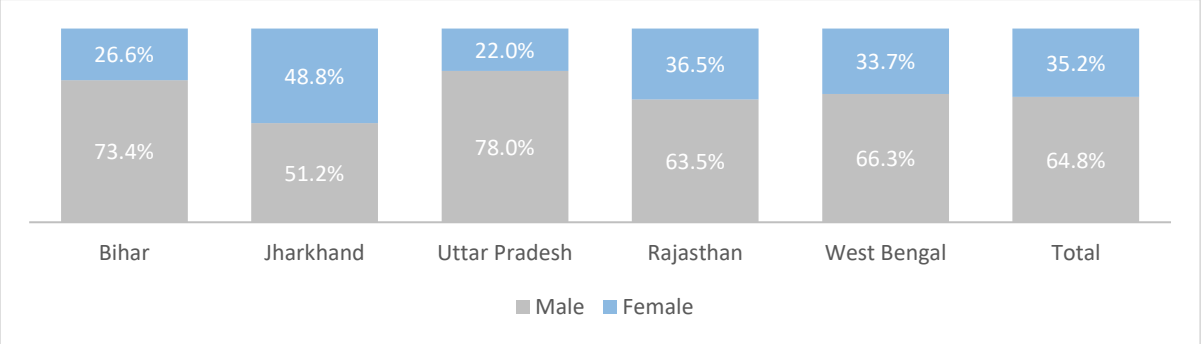


Figure 1 depicts, the beneficiary respondents of the selfcare in the leprosy colonies were the oldest (80.4% in the 45+ category), and the highest percentage of the youngest (<=17) beneficiaries were in the urban leprosy programme (9.8%) followed by the call centre project (6.5%).

Figure 2: Sex Dispersion: State Specific (N=718)



Gender Dynamics:

- Some projects display balanced gender distribution, while others exhibit pronounced imbalances, highlighting the need for gender-sensitive interventions.
- Context-specific approaches are vital to address gender dynamics effectively and ensure inclusivity in leprosy-related initiatives.

Figure 2 depicts, overall, the male beneficiary respondents were almost twice than females (64.8% vs 35.2%). However, in Jharkhand they were almost equal (male 51.2% and female 48.8%).

Education, a cornerstone of empowerment, showcases distinct patterns across various NLR India projects, reflecting the diverse educational backgrounds of participants. Each project addresses the unique needs of individuals with varying levels of educational attainment. The interventions/ messages are accordingly tailored for their understanding and practice.

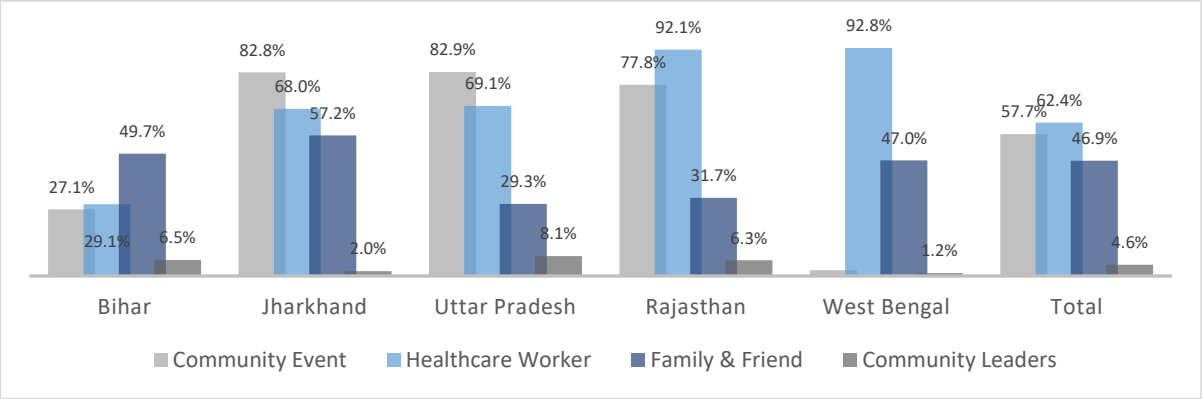
Table 7: Education Level (In Percentage): Project Specific (N=718)

Education Level	Total	HBSC	SCC	SCPHC	CSC	DID	ULP	Vikalp
Never went to school	**39.8**	**59.5**	**62.7**	**23.7**	**41.1**	**26.3**	**43.9**	**16.1**
Less than class 5	13.5	11.9	16.5	1.7	14.3	18.8	9.8	19.4
Completed class 5th	9.9	9.5	6.3	17.8	7.7	8.1	17.1	9.7
Completed class 8th	13.2	7.1	6.3	20.3	14.3	14.4	7.3	25.8
Completed class 10th	17.3	4.8	7.6	27.1	19.0	20.6	14.6	22.6
Completed class 12th	4.2	7.1	0.0	8.5	1.8	6.3	4.9	6.5
Graduation & Above	2.1	0.0	0.6	0.8	1.8	5.6	2.4	0.0

Majority of the respondents in the Self-Care in the Colony project (62.7%) and Home-based Self-Care project (59.5%) never attended school, underscoring the unique challenges faced by these populations. In contrast, the Call Centre (Vikalp) project records the lowest percentage of respondents who never attended school, standing at 16.1%. This suggests a comparatively higher baseline of education among this project's participants. The data reflects variability in the gender of household heads across states, with some states having most male-headed households and others with a higher representation of female-headed households. Across all states, 85% of respondents come from a male-headed household.

Understanding where respondents learned about programmes is vital for optimizing outreach strategies. Health workers (62.4%) and community events (57.7%) seem to be effective channels, emphasizing the importance of community engagement and healthcare personnel in programme dissemination.

Figure 3: Pathways to Project Awareness: State Specific (N=718)



In the journey of project involvement, understanding the channels through which beneficiaries first learn about initiatives is integral to shaping effective outreach strategies. The exploration of these pathways reveals nuanced trends in beneficiary engagement across diverse states.

- **Community Events or Meeting:** In Jharkhand and Uttar Pradesh, community events or meetings emerge as pivotal channels, serving as the entry point for beneficiaries to discover and engage with leprosy care initiatives. Conversely, in West Bengal, the impact of community events or meetings is relatively subdued, indicating that alternative channels may play major role in information dissemination.
- **Health Workers:** Rajasthan and West Bengal showcase a considerable reliance on health workers, particularly ASHA/ANM, highlighting the pivotal role of healthcare professionals in introducing beneficiaries to leprosy care projects. West Bengal sees the highest impact through health workers, underscoring the effectiveness of this personal and direct approach in engaging beneficiaries.
- **Friends/Family Members:** The informal network of friends and family emerges as an important pathway in Bihar, Jharkhand, and West Bengal, showcasing the influential role of personal connections in driving beneficiary involvement.
- **Community Leaders:** While present, community leaders play a minor role as an initial source of information. Their impact is relatively limited compared to other channels, suggesting that alternative pathways may be more influential in driving beneficiary engagement.

Gender Dynamics:

Table 8: Gender Lens on Key Parameters

Key Parameters	N	Female %	Male %
Never went to school	286	54	46
Improvement in knowledge on leprosy	402	33	67
Improvement in knowledge on selfcare	362	33	67
Regular practice of self-care	425	32	68
Participation of leprosy affected in community activities and events	57	42	58
Very positive impact on life and well-being	108	29	71

Key Observations:

1. Females have got less opportunity for education.
2. Females demonstrate lower improvement in knowledge of leprosy and selfcare.
3. Lesser proportion of females regularly practice selfcare. This may be due to less understanding of selfcare, or lack of motivation or less opportunity where males are preferred to get better treatment and care.
4. Lesser proportion of females are participating in community events. This may be due to higher stigma towards females affected by leprosy and disability compared to males.

Disability Care: Specific Insights

Specific Insights: Selfcare Projects

This section delves into the comprehensive assessment of self-care projects, encompassing various dimensions such as awareness enhancement, well-being augmentation, and quality of life improvement among individuals affected by leprosy. Through meticulous data analysis and stakeholder feedback, the report presents a nuanced understanding of the experiences, satisfaction levels, and perceived impact of self-care initiatives implemented across different settings. It offers insights into the effectiveness of these projects in fostering community awareness, promoting individual well-being, and enhancing the overall quality of life for those affected by leprosy. Key outcome harvests from this assessment shed light on successful strategies, challenges encountered, and areas for further improvement. By synthesizing findings, conclusions, and actionable recommendations, this section aims to inform future interventions, optimize programmatic approaches, and ultimately contribute to the holistic well-being of individuals impacted by leprosy.

Homebased Selfcare

Figure 4: Receiving Homebased Selfcare (N=41)

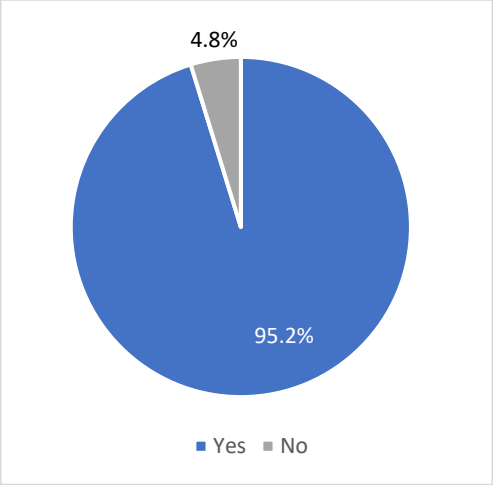


Figure 5: Satisfaction with Homebased Selfcare (N=41)

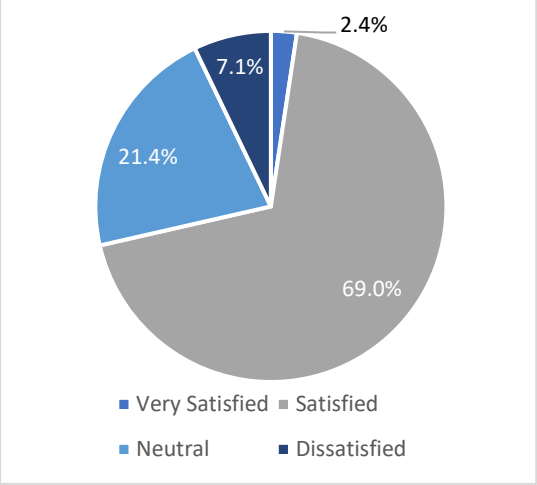


Table 9: HBSC Respondents' Practice of Selfcare: State Specific

N	West Bengal
	42
Yes, regularly	29%
Occasionally	71%
No, not at all	0%

Key Insights:

- 95.2% of respondents received crucial support from Accredited Social Health Activist (ASHA) workers at home, reflecting the project's commitment to empowering individuals.
- 71.4% of beneficiaries expressed satisfaction with home-based self-care support, highlighting the significance of personalized care within familiar surroundings.
- Limited access to assistive and protective devices (only 2.4% of respondents shared having received assistive and preventive devices) prompts examination of distribution processes and barriers hindering resource delivery.

- Universal participation in Training for Selfcare scheme indicates the project's success in disseminating crucial knowledge and skills.

The findings underscore the significance of personalized care provided within the familiar surroundings of one's home, reinforcing the idea that effective self-care is not just about medical assistance but also about the quality of the human connection forged through these interactions. The core observations also include:

- Positive feedback from recipients and widespread participation in training initiatives underscore the project's success.
- Challenges such as limited access to assistive devices highlight areas for enhancement and refinement.
- Nuanced evaluation is essential to optimize the impact of the initiative and address existing gaps effectively.

Selfcare at Colonies

The "Selfcare at Colonies" project, spanning Bihar, Jharkhand, and Uttar Pradesh, paints a vivid portrait of community engagement, self-empowerment, and the nuanced impact of self-care initiatives.

Table 10: Attended Selfcare Training at Colonies – State Specific

N	Bihar	Jharkhand	Uttar Pradesh	Total
	27	100	31	158
Yes	100.0%	86.0%	96.8%	90.5%
No	0.0%	14.0%	3.2%	9.5%

From the vibrant landscapes of Bihar to the diverse cultural tapestry of Jharkhand and the sprawling communities in Uttar Pradesh, each state brings its unique essence to the collective journey toward self-empowerment. The robust attendance at self-care training programmes reflects a strong commitment to learning and adopting self-care practices among beneficiaries.

"Access to health camps and transparent communication are essential. Streamlining processes and making benefits more accessible will greatly improve our ability to receive the intended support." – Beneficiary, FGD

Regular vs. Occasional Self-care Practices:

Table 11: SCC Respondents' Practice of Selfcare: State Specific

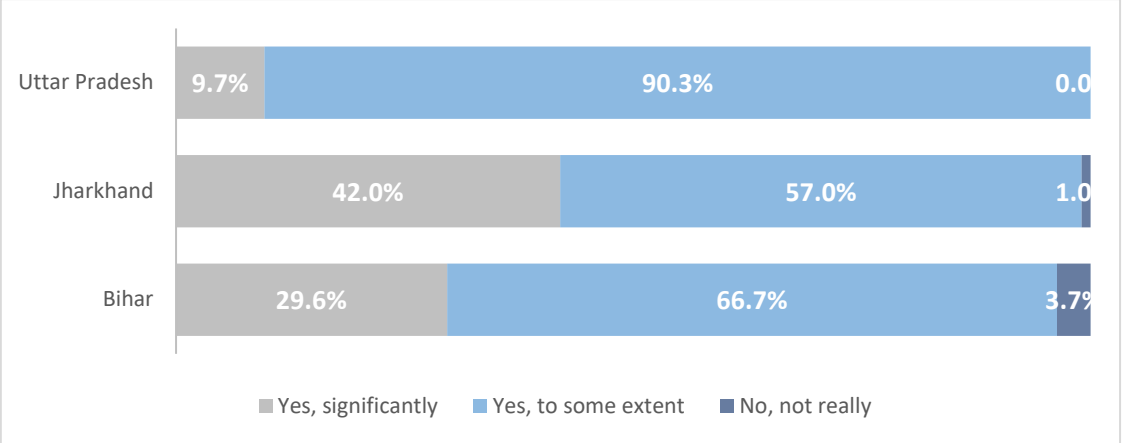
N	Bihar	Jharkhand	Uttar Pradesh	Total
	27	100	31	158
Yes, regularly	100.0	49.0	6.5	49.4
Occasionally	0.0	49.0	93.5	49.4
No, not at all	0.0	2.0	0.0	1.3

Key Observations:

- Bihar demonstrates proactive engagement, with 100% reporting attending and practicing regular self-care practices.

- Jharkhand and Uttar Pradesh exhibit a mix, with occasional practices being more prevalent, highlighting regional variations and the need for targeted efforts.

Figure 6: Perception on Project Impact in Managing Disability - Selfcare at Colonies (N=158)



Diverse Impact on Managing Disabilities:

- Bihar and Jharkhand showcase a substantial positive impact on managing leprosy-related disabilities, underlining the effectiveness of the interventions.
- In contrast, Uttar Pradesh, with its distinct socio-cultural context, reports a lower degree of significance. This divergence emphasizes the imperative of adapting strategies to regional nuances, ensuring inclusivity and relevance for all states.

Access to Schemes and Peer Support:

- Beneficiaries access a spectrum of schemes and services, with notable participation in managing disabilities through self-care and training.
- Variations exist in areas such as early assessment services, distribution of assistive devices, and reconstruction surgeries, necessitating a nuanced and state-specific approach.
- Peer support emerges as a powerful force in fostering community and solidarity across states, enriching the narrative of self-empowerment.
- Limited access to certain services like reorientation and mental health support highlights areas for improvement to enhance the project's holistic impact.

Celebrating achievements and recognizing opportunities for refinement, the narrative underscores the importance of context-aware interventions. It's a story that unfolds differently in Bihar, Jharkhand, and Uttar Pradesh, yet converges on the overarching themes of empowerment, resilience, and the ongoing journey toward holistic well-being. The communal spirit fostered by peer support is a testament to the project's broader impact on social cohesion. Building on this aspect can further fortify the community's resilience and support networks, enriching the narrative of self-empowerment across states.

Selfcare at PHC

The "Selfcare at PHC" project, implemented in Bihar, Uttar Pradesh, and Rajasthan, has demonstrated success in empowering individuals to manage leprosy-related disabilities.

Table 12: Project Impact in Managing Disability - Selfcare at PHC (State Specific)

	Total	Bihar	Uttar Pradesh	Rajasthan
N	118	59	27	32
Yes, significantly	69.5	74.6	43.8%	88.9%
Yes, to some extent	28.0	22.0	53.1%	11.1%
No, not really	2.5	3.4	3.1%	0.0%

Key Observations:

- Over 91% of beneficiaries actively participated in self-care training camps across the three states, showcasing robust interest and commitment to gaining knowledge and skills for self-management.
- 69.5% of beneficiaries report a significant improvement in managing leprosy-related disabilities, highlighting the transformative power of education and practical skills imparted at PHCs.

Table 13: SCPHC Respondent Practice of Selfcare (State Specific)

	Total	Bihar	Uttar Pradesh	Rajasthan
N	118	59	27	32
Yes	76.3%	88.1%	40.6%	92.6%
Occasionally	22.9%	10.2%	59.4%	7.4%
No	0.8%	1.7%	0.0%	0.0%

Practice of Self-care:

- 76.3% of beneficiaries embrace regular self-care practices, emphasizing the sustainability of positive health practices and the project's holistic approach.
- Training on self-care methods plays a pivotal role in empowering individuals, promoting a sense of agency and self-efficacy in dealing with leprosy-related challenges.

Table 14: SCPHC Beneficiaries' Access to Support (In percentage)

Access of Support to Beneficiaries	Grand Total
N	118
Training on Selfcare Methods	63.6
Manage Disability through Selfcare	53.4
GHC/ANM/ASHA at PHC identify and provide early assessment	53.4
Motivation from /ASHA/ANM/GNM	28.8
Peer Support	20.3
Reorientation and Training	2.5
Distributing assistive and protective devices	1.7
Reconstruction Surgeries	1.7
Mental health support	1.7

Access to Support:

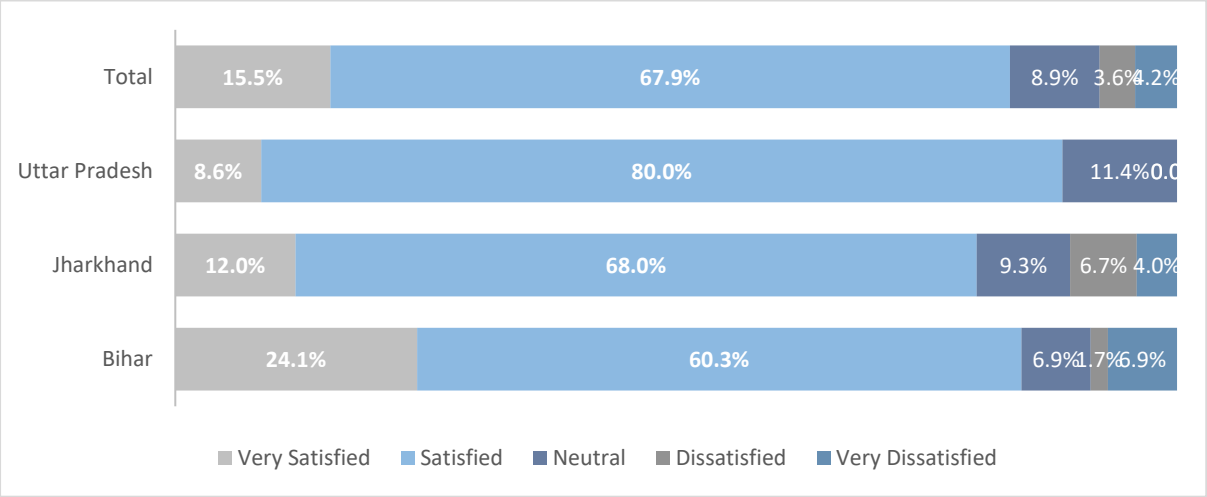
- Proactive healthcare delivery is evident, with 63.6% of beneficiaries accessing early assessment services, reflecting a commitment to early intervention and proactive healthcare.
- Challenges exist in the distribution of assistive devices and accessing reconstruction surgeries, pointing towards areas for improvement and the need for a more seamless delivery of certain services.

In conclusion, the "Selfcare at PHC" project stands as a formidable initiative, with statistical evidence highlighting its success in empowering individuals affected by leprosy. The high participation rates, positive impact on disability management, and consistent practice of self-care underscore the project's effectiveness in fostering independence and holistic well-being. As we navigate the nuanced landscape of successes and challenges, it becomes clear that this project is not merely about addressing health issues; it's a testament to the resilience and agency of individuals on their journey towards improved well-being.

Combined Selfcare

The Combined Selfcare (CSC) project, implemented across Bihar, Jharkhand, and Uttar Pradesh, represents a comprehensive initiative catering to the unique needs of individuals affected by both Leprosy and Lymphatic Filariasis (LF). The project employs a multifaceted approach encompassing training camps, psychological support, assistive devices distribution, and information dissemination.

Figure 7: Satisfaction with the Combined Selfcare Project (N=168)



Attendance and Satisfaction:

- Remarkably high attendance rates were recorded across all three states, with Bihar at 96.6%, Jharkhand at 98.7%, and Uttar Pradesh at 100.0%, demonstrating enthusiasm and commitment to self-care.
- Satisfaction levels with the training provided at CSC camps were notable, with the majority reporting satisfaction, the highest very satisfied respondents were from Bihar (24.1%) followed by Jharkhand (12%) and UP (8.6%).

Table 15: CSC Respondents' Practice of Selfcare: State Specific

N	Bihar	Jharkhand	Uttar Pradesh	Total
	58	**75**	**35**	**168**
Yes, regularly	84.5%	33.3%	85.7%	61.9%
Occasionally	10.3%	66.7%	14.3%	36.3%
No, not at all	5.2%	0.0%	0.0%	1.8%

Table 16: Combined Selfcare Services

Project Services	Bihar	Jharkhand	Uttar Pradesh	Total
N	58	75	35	168
Disability assessment (DA)	48.2%	25.9%	86.7%	60.0%
Support for reconstructive surgeries (RCS)	0.0%	65.3%	45.7%	38.7%
Psychological support (PS)	0.0%	42.7%	0.0%	19.0%

Table 16 depicts, the delivery of the CSC services (DA, RCS and PS is best in Jharkhand, followed by UP and Bihar.

Assistive Devices and Services:

- Provision of assistive devices emerged as a critical pillar of support, with varying percentages across states—36.2% in Bihar, 81.3% in Jharkhand, and 94.3% in Uttar Pradesh, reflecting the project's commitment to addressing unique needs.
- Dissemination of information proved effective in empowering beneficiaries with knowledge about self-care practices and services, although regional disparities indicate the need for tailored communication strategies.
- Addressing regional disparities in access to certain services becomes a focal point, with the project acknowledging differences and emphasizing the importance of tailored communication strategies for inclusivity and relevance in every context.

Holistic Care and Empowerment:

- The CSC project transcends physical care to focus on psychological well-being and overall empowerment, aligning with the intrinsic interplay between physical and mental health.
- High attendance rates, positive satisfaction levels, and effective information dissemination collectively contribute to the holistic care and empowerment of individuals affected by neglected tropical diseases, affirming the project's role as a catalyst for comprehensive well-being.

The Combined Selfcare project emerges as a commendable initiative that transcends the boundaries of physical care. It extends its focus to psychological well-being and overall empowerment, aligning with the intrinsic interplay between physical and mental health. The high attendance rates, positive satisfaction levels, and effective information dissemination collectively contribute to the holistic care and empowerment of individuals affected by these neglected tropical diseases, affirming the project's role as a catalyst for comprehensive well-being.

Perceived Impact

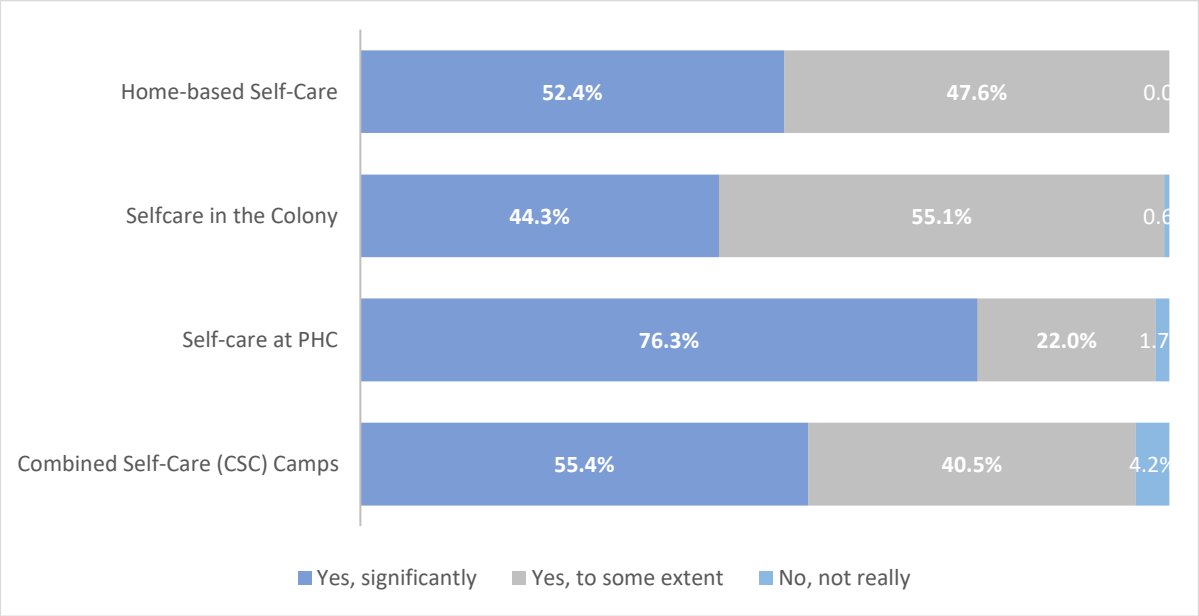
The Knowledge Improvement section of the report delves into crucial dimensions that form the bedrock of effective leprosy care—Leprosy Knowledge, Self-Care Knowledge, and Self-Care Practices. It aims to understand the impact of NLR India's initiatives on enhancing awareness and understanding among individuals affected by leprosy.

In this context, the section critically assesses the degree of knowledge improvement achieved through NLR India's projects, offering insights into the transformative power of informed practices in the realm of leprosy care.

Leprosy Awareness

Understanding the impact of leprosy-focused programmes on knowledge improvement is crucial for ensuring the effectiveness of interventions. The following analysis combines both state and programme perspectives to provide a comprehensive overview of respondents' perceptions regarding knowledge enhancement.

Figure 8: Improved Leprosy Knowledge – Project Specific (N 486) (HBSC: 42; CSC: 168; SCC: 158; SCPHC: 118)



Key Observations:

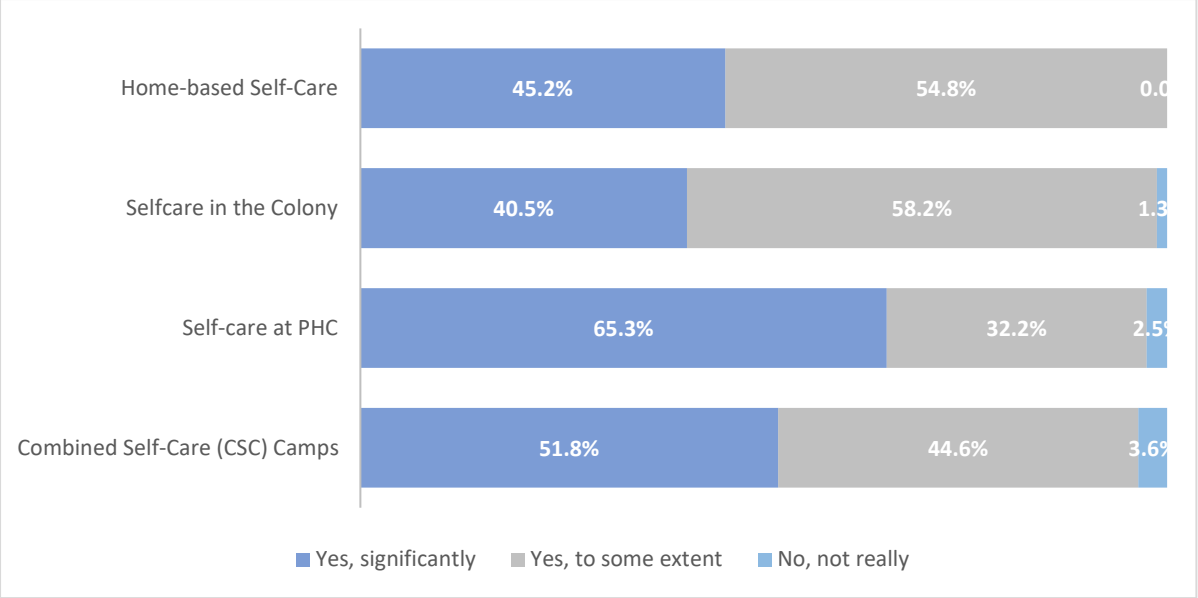
- Self-Care at PHC stands out with 76.3% reporting significant improvement in respondents' knowledge about leprosy, highlighting the effectiveness of educational components within the programme.

I learned about Leprosy disease when I was young. There's a misconception in society. People need to understand it's not something contagious. Government initiatives have helped in dispelling myths – Beneficiary, FGD

Selfcare Awareness

This section delves into the evaluation of knowledge improvement regarding self-care awareness among individuals participating in various leprosy-related programme. The data presented includes insights from different states and specific projects, shedding light on the impact of these initiatives on enhancing awareness and understanding of self-care practices. The findings provide valuable insights for tailoring self-care initiatives to enhance regular engagement and adherence to practices.

Figure 9: Improvement in Selfcare Awareness - Project Specific (N 486) (HBSC: 42; CSC: 168; SCC: 158; SCPHC: 118)



Key Observations:

- Self-Care at PHC emerges as a standout performer, boasting the highest percentage of self-care awareness.
- Combined Self-Care (CSC) Camps also demonstrate substantial percentages of self-care awareness.

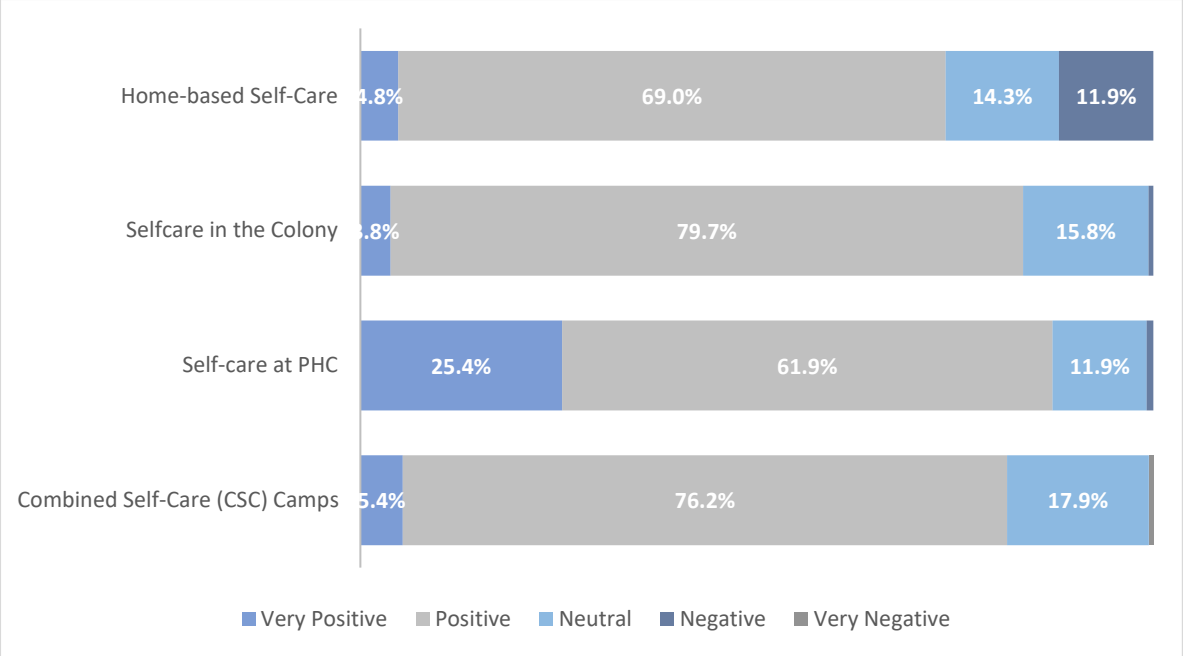
"Self-care practices are the foundation of our well-being. Keeping our surroundings clean and engaging in physical activities are simple yet powerful ways to prevent health issues in our community."

- Beneficiary, FGD

Life & Well Being

The evaluation of life and well-being perceptions among individuals affected by leprosy across various projects and states provides crucial insights into the holistic impact of NLR India's initiatives. This section delves into respondents' outlooks, capturing sentiments ranging from "Very Positive" to "Negative." Additionally, state-wise variations in life and well-being perceptions are explored, shedding light on the diverse experiences of respondents. The overall trend indicates a positive life and well-being perception among respondents, with variations observed across projects and states.

Figure 10: Perceived Project Impact on Life & Well-Being (N 486) (HBSC: 42; CSC: 168; SCC: 158; SCPHC: 118)



Key Observations:

- Overall, respondents across various projects and states demonstrate positive perceptions of life and well-being, with variations observed.
- Projects like Combined Self-Care at PHC, Self-Care (CSC) Camps, Selfcare in the Colony, and Home-based Self-Care receive remarkably positive responses, showcasing a sense of well-being among participants.

"Health Programmes have positively impacted our daily lives. The emphasis on self-care practices and the tangible improvements in well-being showcase the significance of these initiatives." – Beneficiary, FGD

Assistive Devices:

Table 17: Assistive Devices Impacted Mobility & Quality of Life - Project Specific (N 239) (HBSC: 9; CSC: 86; SCC: 61; SCPHC: 83)

Responses	CSC	SCPHC	SCC	HBSC
Yes, significantly	54.7%	45.8%	59.0%	22.2%
Yes, to some extent	25.6%	28.9%	36.1%	0.0%
No, not really	19.8%	25.3%	4.9%	77.8%

Variation Across Projects:

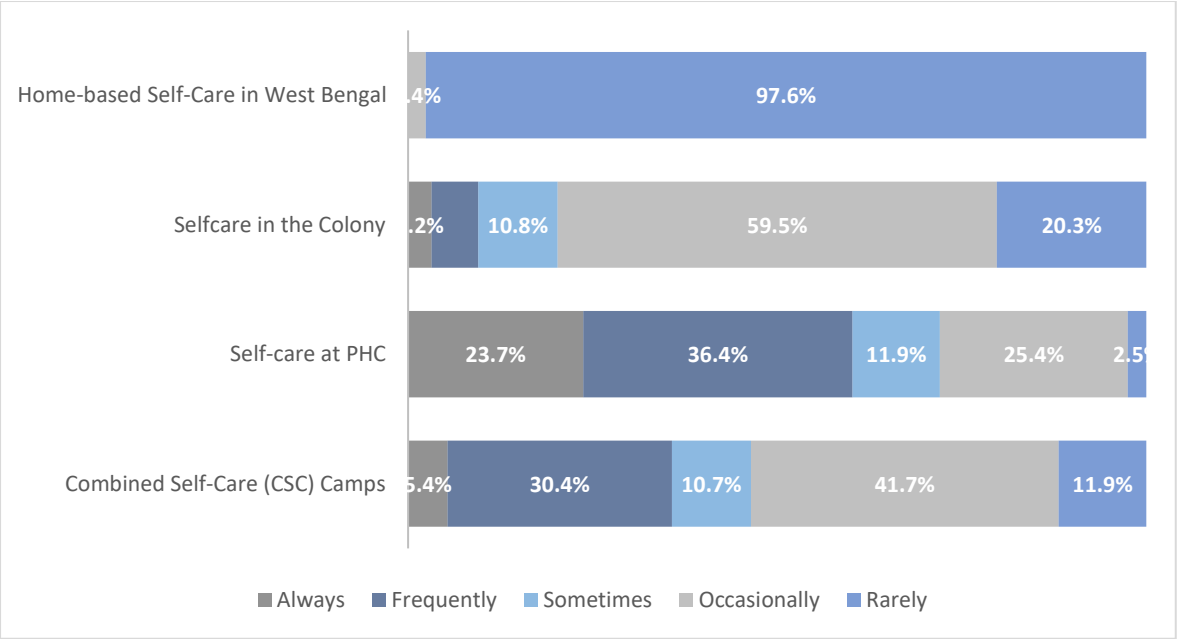
- Home-based Self-Care: Although lower, 22.2% reported a significant positive impact, suggesting the relevance of assistive devices even in home-based care scenarios.
- Selfcare in the Colony: 59.0% reported a significant positive impact, indicating the importance of assistive devices in improving daily functioning within colony settings.

- Self-Care at PHC: 45.8% reported a positive impact, emphasizing the role of these devices in enhancing mobility and quality of life.
- Combined Self-Care (CSC) Camps: 54.7% of respondents reported a significant positive impact, highlighting the effectiveness of assistive devices in this project.

Social Participation

72.4% of respondents reported a positive increase in social support, indicating the positive impact of the projects on social relationships. The social participation section delves into the community engagement, perceived support from the community, confidence in community involvement, and participation in community development initiatives.

Figure 11: Frequency in Community Events (N 486) (HBSC: 42; CSC: 168; SCC: 158; SCPHC: 118)



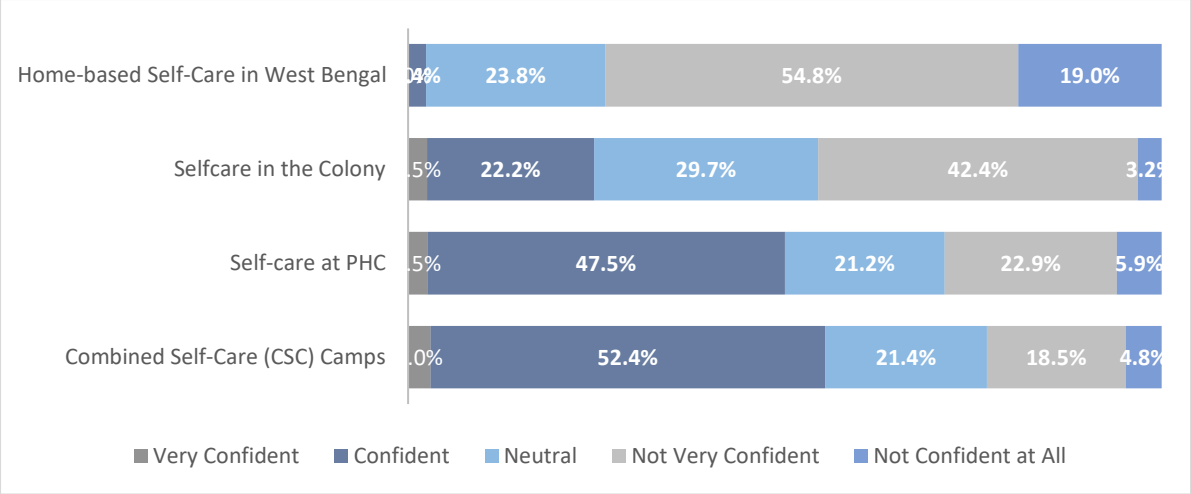
Key Observations:

- Home-based Self-Care: Shows a high percentage of respondents rarely participating in community activities.
- Combined Self-Care (CSC) Camps and Selfcare at PHC (SCPHC): Exhibit notable percentages of respondents engaging frequently or always, indicating more active community involvement.

Community Involvement:

The data explores the confidence levels of respondents in participating in community discussions and decision-making processes. Majority of respondents, especially in Bihar, expressed confidence, though there were variations across states.

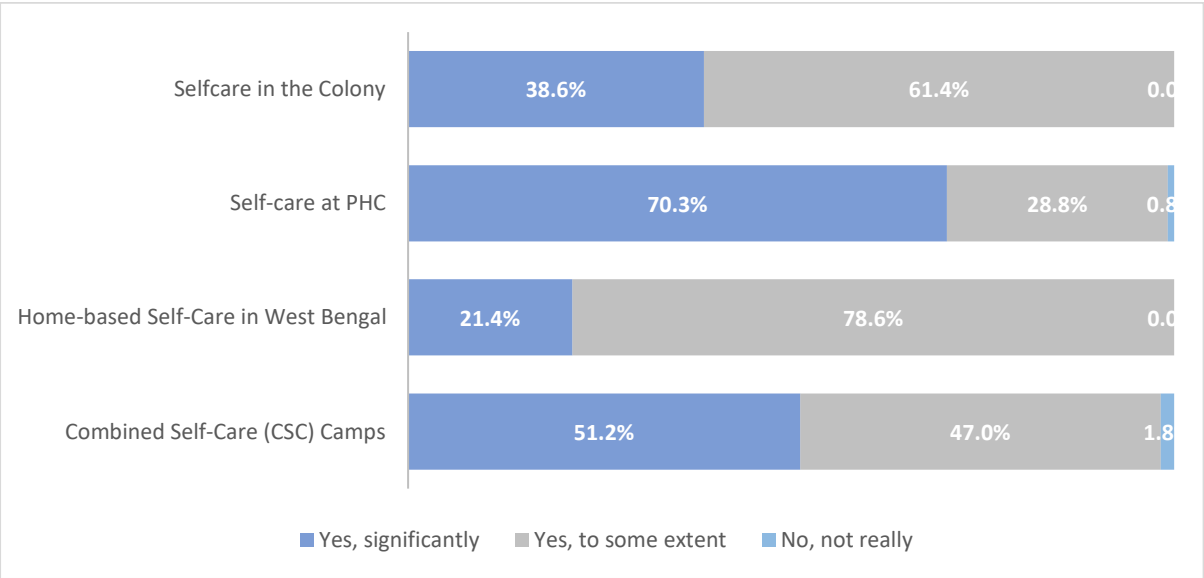
Figure 12: Confidence in Participation in Community Decision-Making (N 486) (HBSC: 42; CSC: 168; SCC: 158; SCPHC: 118)



Project-specific data reveals varying confidence levels in community participation across different projects. Home-based Self-Care participants stand out with a notable percentage of respondents not confident at all. Combined Self-Care (CSC) Camps, on the other hand, has the highest percentage of respondents expressing confidence in community discussions and decision-making processes.

"Historical discrimination has been tough. We faced societal biases due to health conditions, but we stand united. We're overcoming these challenges together."
- Beneficiary, FGD

Figure 13: Project Involvement Helped Raise Awareness in Communities - Project Specific (N 486) (HBSC: 42; CSC: 168; SCC: 158; SCPHC: 118)



Key Observations

- Self-Care at PHC is most effective in raising awareness in the community, followed by Self-Care in Colony, Combined Self-Care (CSC) Camps, and Home-based Self-Care.
- Contextual variations across projects highlight the importance of tailoring awareness strategies to specific project goals and community contexts.

The findings collectively highlight a positive impact on social participation, community engagement, and the development of confidence in community involvement. The involvement in community development initiatives in several states reflects the successful empowerment of respondents, translating acquired skills into active contributions within their communities.

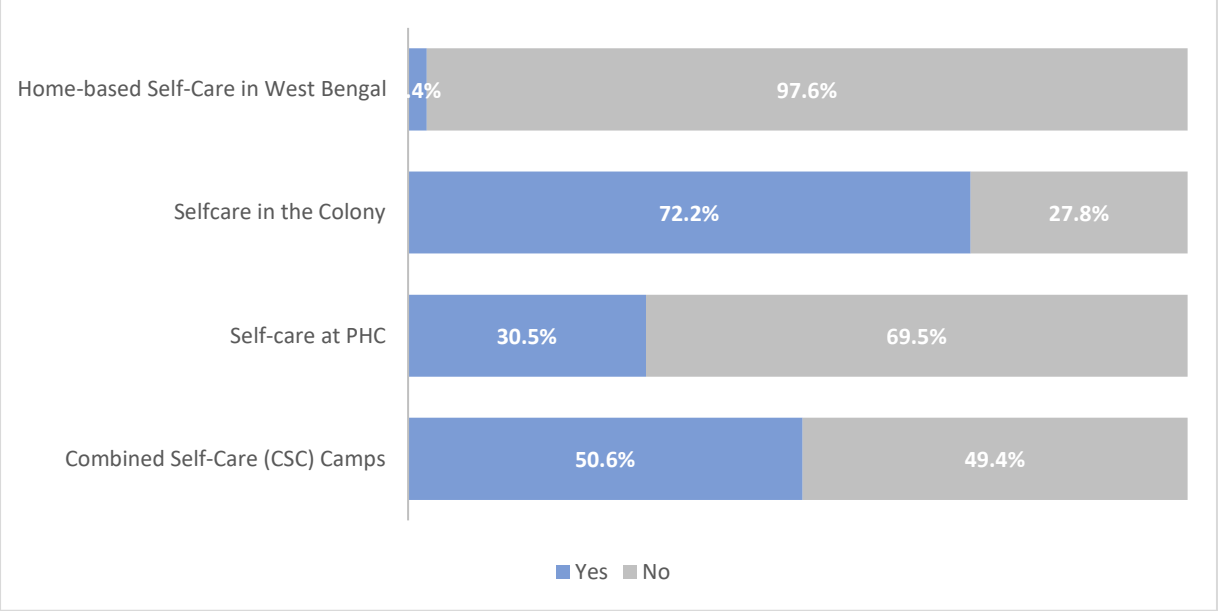
Economic Impact

The survey delved into the transformative effects of projects on income generation, vocational skills, and financial management among the participants. The insights gained from the responses paint a nuanced picture of the projects' influence on the economic aspects of the respondents' lives.

Income Generation:

The programme specific findings regarding income generation aspect reflects diverse outcomes across projects, requiring tailored strategies to address specific challenges and capitalize on successes.

Figure 14: Perceived Impact on Income Generation (N 486) (HBSC: 42; CSC: 168; SCC: 158; SCPHC: 118)



Key Observations:

- Selfcare at Colony stands out with 72.2% of participants reporting improved livelihoods, followed by CSC (50.6%) and Selfcare at PHC (30.5%).

Estimates of Income Increase

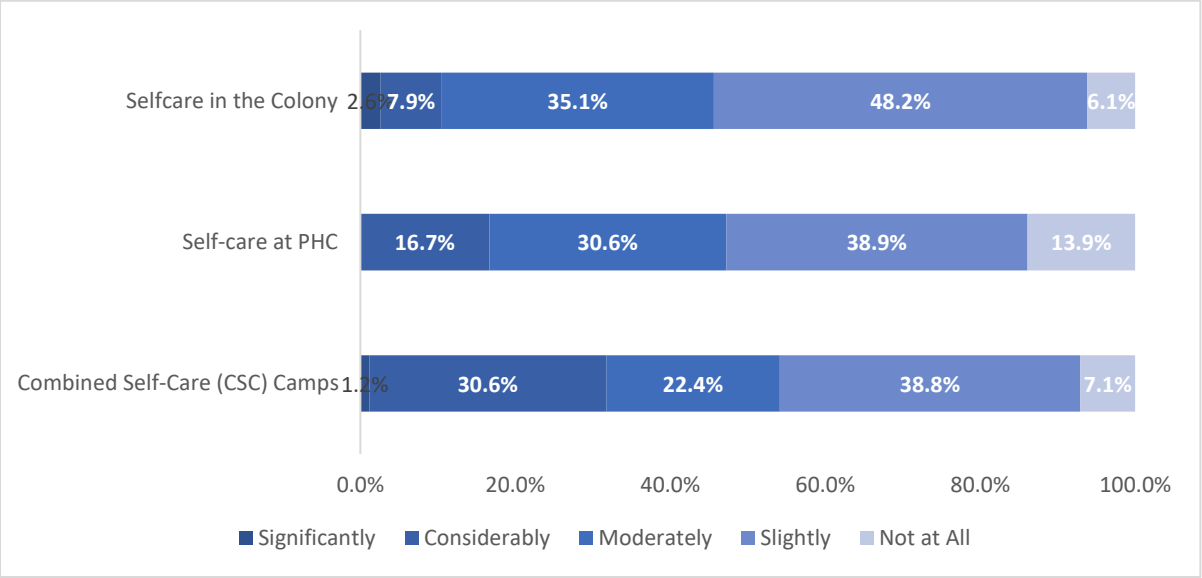
Respondents who reported an increase in monthly income provided estimates across various ranges. The majority fell into the "No Change" category emphasizing the diverse economic backgrounds of the participants. Most participants across Self-Care in leprosy colonies (SCC) projects (around 71%), reported having a positive change in income followed by CSC (around 45%) and SCPHC (around 21%), emphasizing the significance of these initiatives in providing income-generating opportunities. The qualitative interactions highlighted that even though the wages are same, the work the beneficiaries are undertaking is more skill based and respectable from societal perspectives like small scale entrepreneurship e.g. instead of begging.

Table 18: Increase in Monthly Income - Project Specific (N 486) (HBSC: 42; CSC: 168; SCC: 158; SCPHC: 118)

Increase in Monthly Wages	CSC	SCPHC	SCC	HBSC
No Change	55.4%	78.8%	29.1%	100.0%
100-500	23.8%	6.8%	17.1%	0.0%
500-1000	10.1%	4.2%	27.8%	0.0%
1000-2000	5.4%	7.6%	13.3%	0.0%
2000-5000	3.6%	1.7%	6.3%	0.0%
5000-10000	1.2%	0.0%	5.1%	0.0%
Over 10000	0.6%	0.8%	1.3%	0.0%

Vocational Skills and Employability Enhancement:

Figure 15: Project Helped Increase Vocational Skills - Project Specific (N 444) (CSC: 168; SCC: 158; SCPHC: 118)



Key Observations:

- Participants across projects reported varying degrees of enhancement in vocational skills. This intervention is not done in HBSC. The responses indicate that some projects have moderately to greatly contributed to enhancing participants' employability, suggesting positive outcomes in skill development.

Financial Management:

Participants' perceptions of the influence of project support on financial management indicated a multifaceted impact.

Table 19: Beneficiary Financial Practices: Disability Care (N 486) (HBSC: 42; CSC: 168; SCC: 158; SCPHC: 118)

Projects	CSC	HBSC	SCPHC	SCC
N	168	42	118	158
Save a portion of my income regularly	72.6%	61.9%	70.3%	72.2%
Confidence in making financial decisions	39.3%	19.0%	5.9%	31.0%
Establish an emergency fund	28.0%	2.4%	9.3%	20.3%
Community-based financial support system	13.1%	0.0%	1.7%	27.8%
Access microfinance opportunities	4.8%	0.0%	0.0%	3.8%
Access to formal banking services	1.8%	0.0%	2.5%	3.8%

Key Observations:

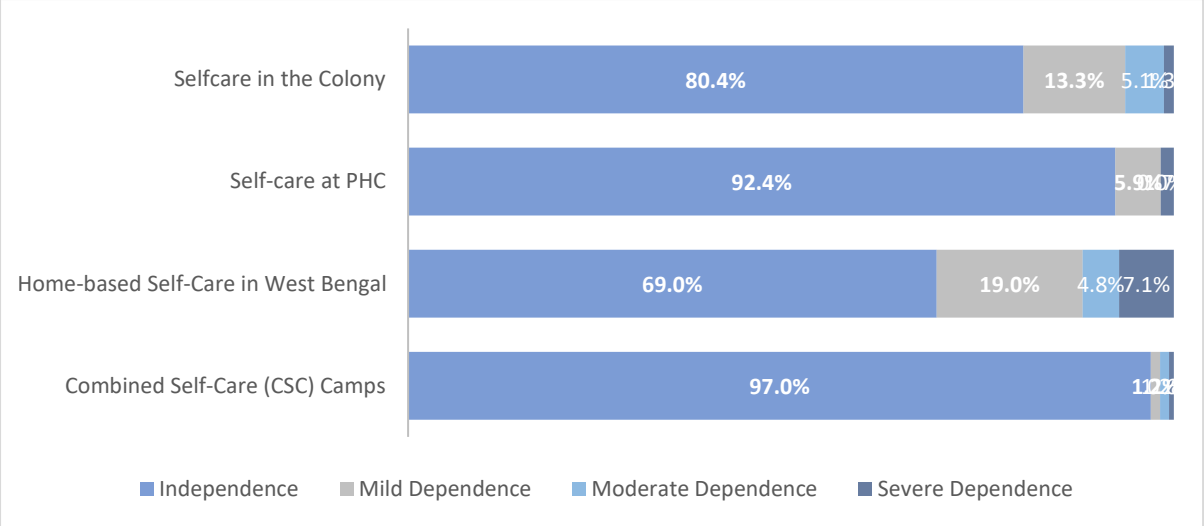
- Over half of the participants reported regularly saving a portion of their income, and a substantial percentage acknowledged access to financial education.
- Combined Self-Care (CSC) Camps projects reported particularly high percentages in positive financial literacy practices.

The analysis underscores the diverse impact of projects on income generation, vocational skills, and financial literacy. While some projects excel in specific areas, others present opportunities for refinement. The findings serve as a foundation for continuous improvement, ensuring that participants derive maximum economic benefits from these initiatives.

ADL & IADL

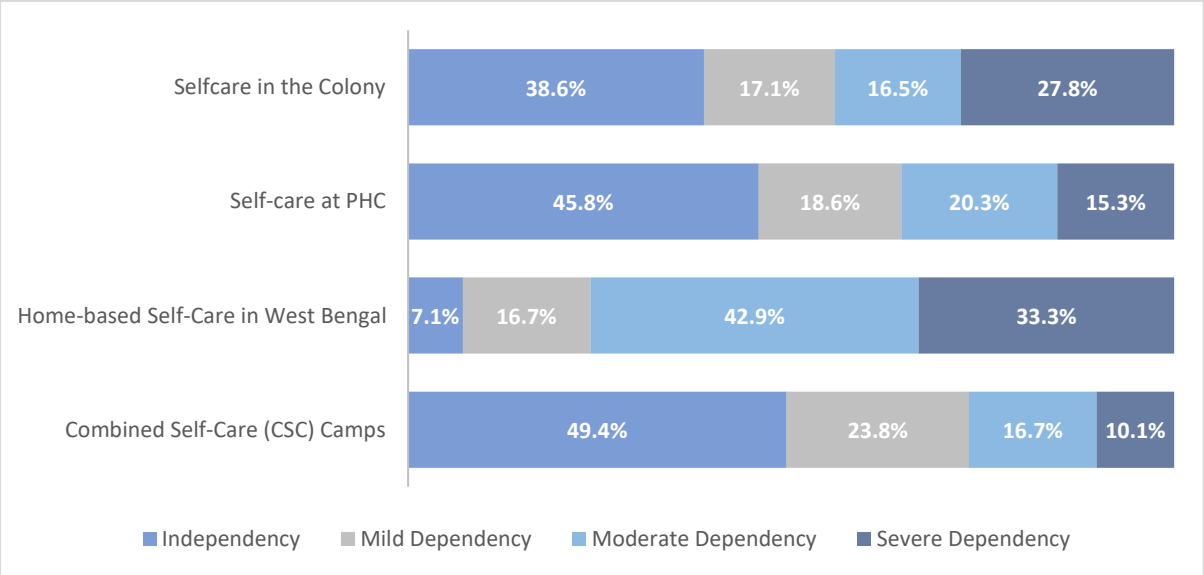
The evaluation of Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) across NLR India's projects unveils a nuanced landscape of successes and challenges. For ADL Independence, the Combined Self-Care (CSC) Camps demonstrate remarkable success with an impressive 97%, showcasing the project's effectiveness in promoting self-care and daily living activities. However, a noticeable gap emerges in IADL Independence (49.4%), signifying the need for targeted interventions to enhance instrumental activities.

Figure 16: ADL Scale - Project Specific (N 486) (HBSC: 42; CSC: 168; SCC: 158; SCPHC: 118)



The analysis prompts several strategic considerations for future interventions. Leveraging successful strategies from high-performing projects and states to tailor interventions is a key recommendation. Addressing specific ADL and IADL challenges in Uttar Pradesh through targeted programme is crucial. Recognizing the interconnectedness of ADLs and IADLs, emphasizing a holistic approach to promote overall independence, is essential.

Figure 17: IADL Scale - Project Specific (N 486) (HBSC: 42; CSC: 168; SCC: 158; SCPHC: 118)



Key Observations:

- Home-based Self-Care exhibits moderate success in ADL Independence (69%), while IADL Independence (7.1%) emerges as a critical area for improvement, necessitating focused interventions to address challenges in daily living.
- Selfcare in the Colony demonstrates positive outcomes in ADL Independence (80.4%) but moderate self-reliance in IADL Independence (38.6%), requiring continuous support for improvement.
- Self-care at PHC boasts high success in ADL Independence (92.4%) but reveals a moderate success in IADL Independence (45.8%), indicating the need for targeted efforts to enhance independence in instrumental activities.
- Combined Selfcare (CSC) depicts the highest success in both ADL and IADL independence 97% and 49.4% respectively.

Developing interventions that integrate both self-care and instrumental activities to enhance daily living for individuals affected by leprosy is a pivotal step. Involving communities in the co-creation of interventions, ensuring they are culturally sensitive and community-driven, is imperative. Fostering community support networks to complement project-based initiatives is another crucial aspect. Implementing continuous monitoring mechanisms to track progress across ADLs and IADLs and fostering a culture of adaptability and learning for iterative improvements in interventions are essential. Focusing on capacity building at the individual and community levels, empowering individuals to take charge of both ADLs and IADLs, and providing education and resources to enhance skills in self-care and instrumental activities are vital considerations. In conclusion, the integration of ADL and IADL findings underscores the importance of a comprehensive and interconnected approach to supporting individuals affected by leprosy. Tailored interventions, community involvement, continuous monitoring, and capacity building emerge as pivotal elements shaping the next phase of interventions to enhance independence and well-being.

Outcome Harvesting

Table 20: Outcome Harvesting: Disability Care Projects

Project	Key Outcomes	Supporting Evidence
Homebased Selfcare	Improved Health Outcomes	73.8% of the project population have had very positive to positive experience of overall life & well-being.
	Empowerment Through Knowledge	100% of the project beneficiaries reported an increase in both leprosy related and selfcare method knowledge.
Selfcare at Colonies	Enhanced Community Participation in Self-Care	71.5% of beneficiaries heard about the intervention through a community event/meeting. 100% of the respondents reported increase in the community awareness regarding leprosy out of which 38.6% reported a significant change.
	Strengthened Social Support Networks	59.5% go to community events at least occasionally, with an overall 79.7% of respondents being involved in social events. 81.6% of respondents experienced increased support from community towards their disability.
Selfcare at PHC	Increased Adherence to Self-Care Practices	99.2% of beneficiaries responded with practicing selfcare methods, of which 76.3% practice selfcare regularly.

Project	Key Outcomes	Supporting Evidence
	Improved Health Literacy and Empowerment	74.7% of beneficiaries reported a positive impact of the assistive devices provided. 97.5% of the survey population reported improved knowledge on selfcare methods (of which 65.3% reported a significant change) Similar trends are observed in Leprosy Knowledge with 98.3% of population responding with an affirmative response.
Combined Selfcare	Enhanced Self-Efficacy and Independence	97% of the population was reported to be in the "Independent" zone in ADL Scale.
	Strengthened Social Support Networks	55.4% of the population feel confident in participating in community events. 88.1% of beneficiaries visit community events or meetings at least occasionally. Qualitative inputs suggested the respondents experienced increased social support from community members post implementation of the project.

Conclusions

Home Based Selfcare

The Home-Based Self-Care Project has revolutionized disability care by providing essential support directly to individuals affected by leprosy in their homes. With high satisfaction levels among beneficiaries and widespread participation in training initiatives, the project has effectively addressed the needs of beneficiaries. Moving forward, continued collaboration and innovation are essential to meet the evolving needs of individuals affected by leprosy, focusing on enhancing access to assistive devices and strengthening community partnerships.

1. Revolutionized disability care through home-based support for individuals affected by leprosy.
2. ASHA workers provided personalized self-care assistance, fostering trust and confidence in community-based care.
3. 95.2% satisfaction rate among respondents in West Bengal.
4. Challenges addressed with resilience and adaptability.
5. Increased awareness and utilization of self-care resources observed.

Selfcare at Colonies

The Selfcare at Colonies project has promoted improved self-care practices and positive community dynamics among residents of leprosy colonies. With strong community engagement and acceptance, the project has empowered individuals to take ownership of their health and well-being. Sustained support and collaboration are crucial to address the ongoing needs of residents in leprosy colonies, prioritizing strengthening community partnerships and expanding access to essential services.

1. Promoted improved self-care practices among residents of leprosy colonies.
2. 92.0% reported regular self-care practices in Jharkhand.
3. Positive acceptance by the government health system and the community.
4. Resilient to implementation challenges with increased awareness and utilization of self-care resources.

Selfcare at PHC

The Selfcare at Primary Health Centres (PHC) project has empowered individuals affected by leprosy to manage their disabilities effectively. With widespread participation in self-care training camps and positive feedback, the project has disseminated crucial knowledge and skills. Continued collaboration and innovation are needed to

sustain the momentum gained, focusing on enhancing access to assistive devices and integrating self-care training into routine healthcare services.

1. Empowered individuals affected by leprosy through self-care training camps.
2. Over 91% beneficiaries participated in training camps across Bihar, Uttar Pradesh, and Rajasthan.
3. 69.5% reported significant improvement in managing leprosy-related disabilities.
4. Notable behavioral change observed with increased awareness and utilization of self-care resources.

Combined Selfcare:

The Combined Self-Care (CSC) Camps project has empowered individuals affected by leprosy and Lymphatic Filariasis (LF) to take control of their health and well-being. With high attendance rates and positive feedback, the project has effectively engaged marginalized populations and delivered essential services. Sustained support and collaboration are essential to address the evolving needs of individuals affected by neglected tropical diseases (NTDs), prioritizing strengthening partnerships and expanding access to assistive devices.

1. Empowered individuals affected by leprosy and Lymphatic Filariasis (LF) through comprehensive support.
2. High attendance rates exceed 95% across Bihar, Jharkhand, and Uttar Pradesh.
3. Remarkable acceptability by the government health system and the community.
4. Notable behavioral change observed with increased awareness and utilization of self-care resources.

Comparative Factsheet

Table 21: Comparative Factsheet: Disability Care (N 486) (HBSC: 42; CSC: 168; SCC: 158; SCPHC: 118)

Projects	CSC	HBSC	SCPHC	SCC
Improvement in Leprosy Awareness	55.4	52.4	76.3	44.3
Improvement in Selfcare knowledge	51.8	45.2	65.3	40.5
Regular Practice of Selfcare Methods	61.9	28.6	76.3	49.4
Positive impact on overall life and well-being	81.5	73.8	87.3	83.5
ADL Independence	97	69	92.4	80.4
IADL Independence	49.4	7.1	45.8	38.6
Average	**66.2**	**46.0**	**73.9**	**56.1**

Comparison of the four different selfcare models across the six different parameters ranks the selfcare at PHC (SCPHC) as the best followed by combined selfcare (CSC), selfcare at leprosy colonies (SCC) and home-based selfcare (HBSC). However, each of them has their unique advantages.

Recommendations

Homebased Selfcare

1. Scale-up Home-Based Selfcare beyond West Bengal (existing).
2. Home based care may also be started for lymphatic filariasis.
3. Besides selfcare, home based care may also provide psycho-social support.
4. The supply of MCR shoes and other assistive devices may be improved.
5. May also create peer supporters for enhanced support to the affected.
6. Mobilize support for livelihood through inter-departmental linkage e.g. Krishi Vikas Kendra (KVK) and State Livelihood Mission (SLM).
7. Make provision for customization of MCR shoes.
8. The monitoring system may be improved.
9. Introduce quarterly ADL and IADL assessment.
10. GIS mapping of the persons with disabilities.

Selfcare at Colonies

1. Regularize visit of frontline workers to leprosy colonies.
2. Train frontline workers to provide selfcare services in a group.
3. Besides selfcare, they can also provide psycho-social support.
4. Form self-care groups.
5. Provide MCR shoes (preferably customized) and other assistive devices.
6. Create peer supporters for enhanced support to the affected.
7. Mobilize support for livelihood through inter-departmental linkage e.g. Krishi Vikas Kendra (KVK) and State Livelihood Mission (SLM) as applicable.
8. Introduce monitoring system.
9. Conduct quarterly ADL and IADL assessment.
10. GIS mapping of the persons with disabilities.

Selfcare at PHC

1. Strengthen PHC-Based Selfcare service: Selfcare intervention is a part of government Disability Prevention and Medical Rehabilitation (DPMR) services. NLRIF advocated model may be implemented by the PHCs.
2. Strengthen delivery of DPMR service including selfcare during and after completion of multi drug therapy (MDT) for leprosy (released from treatment, RFT).
3. Conduct monthly camp for selfcare.
4. Mobilize attendance through communication with local leaders and frontline workers.
5. Develop peer supporters for stronger linkage with the community and psycho-social support.
6. Use appropriate IEC materials for promoting selfcare.
7. Maintain appropriate stock of MCR shoes and other assistive devices.
8. Make provision for customization of MCR shoes.
9. Mobilize support for livelihood through inter-departmental linkage e.g. Krishi Vikas Kendra (KVK) and State Rural Livelihood Mission (SRLM).
10. Introduce quarterly ADL and IADL assessment.
11. GIS mapping of the persons with disabilities.

Combined Selfcare

1. Introduce combined selfcare for leprosy and LF in PHCs with leprosy and LF endemicity.
2. Strengthen delivery of DPMR and morbidity management and disability prevention (MMDP) services through PHCs.
3. Conduct monthly camp for selfcare.
4. Mobilize attendance through communication with local leaders and frontline workers.
5. Develop peer supporters for stronger linkage with the community and psycho-social support.
6. Use appropriate IEC materials for promoting selfcare.
7. Maintain appropriate stock of MCR shoes and other assistive devices.
8. Make provision for customization of MCR shoes.
9. Mobilize support for livelihood through inter-departmental linkage e.g. Krishi Vikas Kendra (KVK) and State Rural Livelihood Mission (SRLM).
10. Introduce quarterly ADL and IADL assessment.
11. GIS mapping of the persons with disabilities.

Disability Inclusive Development: Specific Insights

Specific Insights: Disability Inclusive Development

The Disability Inclusive Development (DID) project, implemented in Bihar, Jharkhand, and Uttar Pradesh, aims to empower individuals affected by leprosy through community-based initiatives and collaborations with self-help groups (SHGs) and Organizations of Persons with Disabilities (OPDs).

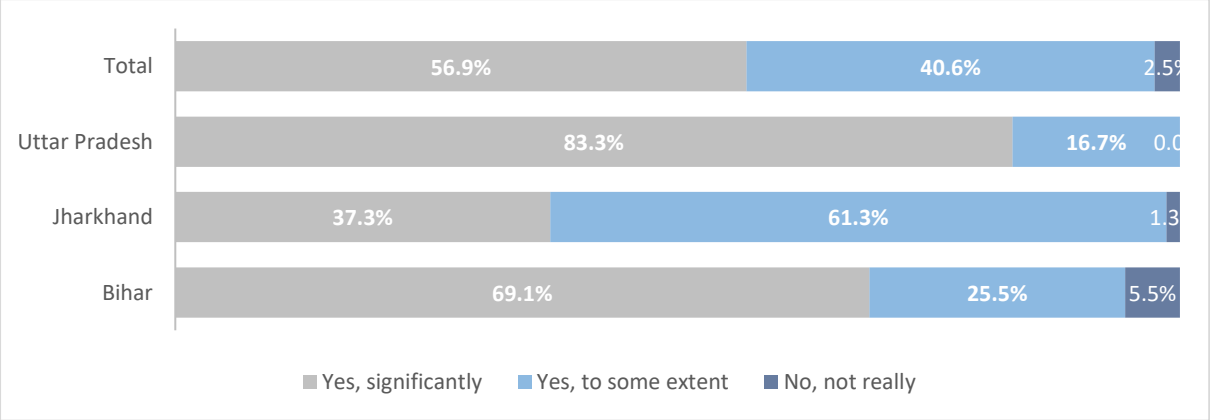
The project unfolds as a transformative force, amplifying the voices and influence of individuals affected by leprosy within their communities. Survey findings reveal that most participants in Bihar (98.2%), Jharkhand (100.0%), and Uttar Pradesh (76.7%) are active members of SHGs or OPDs facilitated by the DID project. This indicates a strong presence and active engagement of leprosy-affected individuals in community-based institutions.

Table 22: DID Beneficiary being an SHG/CBO Member (N=160)

N	Total	Bihar	Jharkhand	Uttar Pradesh
	160	55	75	30
Yes	95.0	98.2	100.0	76.7
No	5.0	1.8	0.0	23.3

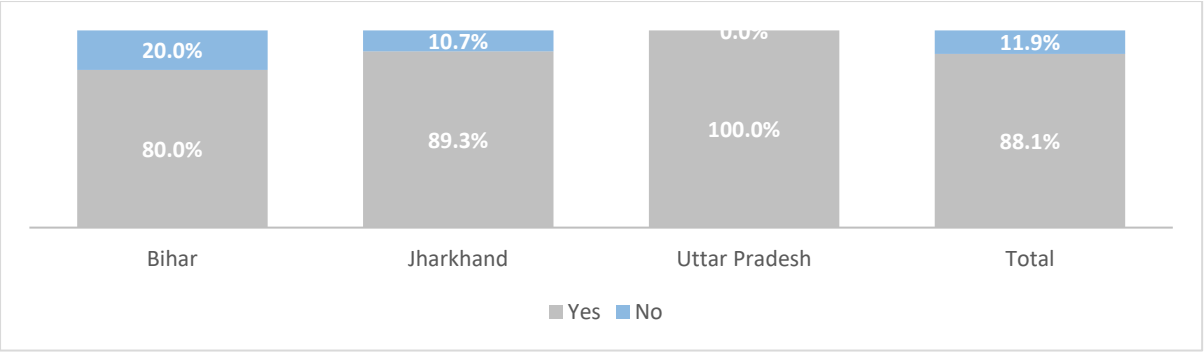
A substantial 56.9% of participants report significant empowerment, showcasing the project's success in fostering confidence and influence among its beneficiaries.

Figure 18: Perception on Empowerment: DID (N=160)



Recognizing the unique needs of individuals affected by leprosy, the project's commitment to timely interventions contributes to its positive impact. Quality takes centre stage, with an overwhelming 88.1% of participants expressing satisfaction with the calibre of support and services provided. This endorsement underscores the project's ability to not only meet but surpass participant expectations, creating an environment of trust and reliability.

Figure 19: Services Contentment Amongst DID Beneficiaries: State Specific (N=160)



Key Observations:

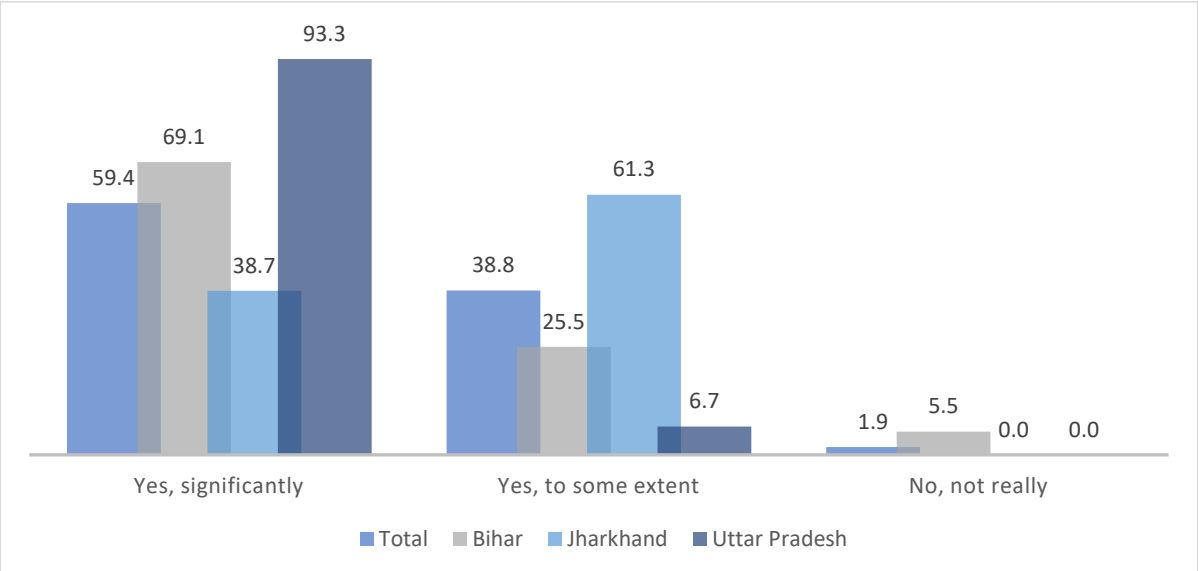
- Notable improvement in understanding of leprosy among participants across Bihar, Jharkhand, and Uttar Pradesh.
- Bihar demonstrates robust uptake of knowledge, Jharkhand presents diverse responses, and Uttar Pradesh showcases remarkable progress.

The DID project emerges not only as a response to physical impairments but as a catalyst for community change. It creates an environment where individuals affected by leprosy are not defined by their condition but are empowered to actively shape their destinies. The amalgamation of empowerment, timely support, and high-quality interventions solidifies the project's role in shaping positive narratives and building a future where individuals affected by leprosy are agents of their own well-being.

Perceived Impact

Selfcare Awareness

Figure 20: DID Involvement Improved Selfcare Knowledge – State Specific (In Percentage, N=160)



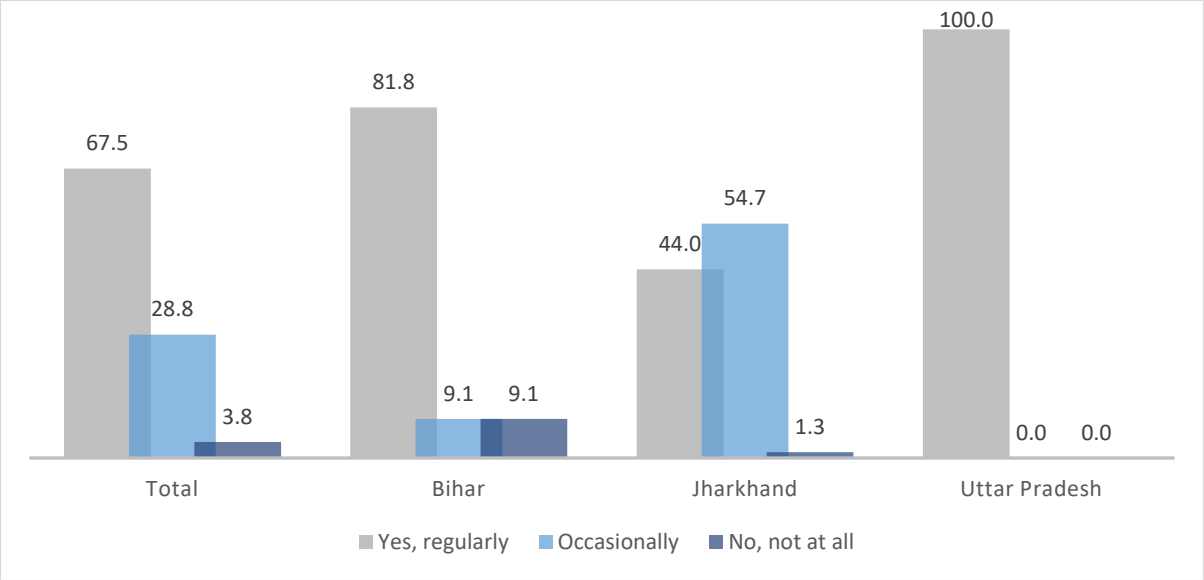
Key Observations:

- Bihar: In Bihar, 69.1% of participants expressed a significant enhancement in their knowledge about leprosy. While a smaller proportion (25.5%) reported improvement to some extent, the state demonstrates a robust uptake of knowledge among beneficiaries.
- Jharkhand: Jharkhand presents a unique landscape, with 38.7% of participants citing a significant improvement in their understanding of leprosy. Interestingly, a larger segment (61.3%) reported improvement to some extent, indicative of the diverse responses within the state.
- Uttar Pradesh: Uttar Pradesh emerges as a frontrunner in knowledge enhancement, with an impressive 93.3% of participants attesting to a significant improvement. The state showcases remarkable progress, reflecting the project's profound impact on knowledge dissemination within communities.

Selfcare Practice

As part of the holistic approach to empowerment, the Disability Inclusive Development (DID) project places a strong emphasis on fostering self-care practices among beneficiaries. This section explores the prevalence of self-care methods among beneficiaries across Bihar, Jharkhand, and Uttar Pradesh, shedding light on their commitment to personal well-being.

Figure 21: DID impacted Selfcare Practice - State Specific (In Percentage, N=160)



Key Observations:

1. Bihar: The majority of beneficiaries in Bihar (81.8%) demonstrate a commendable commitment to self-care, practicing methods regularly to maintain their health and well-being.
2. Jharkhand: While the prevalence of regular self-care practices is slightly lower in Jharkhand (44.0%), a considerable proportion of beneficiaries (54.7%) engage in self-care methods occasionally, indicating varying levels of adoption within the state.
3. Uttar Pradesh: Uttar Pradesh presents an encouraging picture, with 100% of beneficiaries practicing self-care methods regularly, showcasing a strong dedication to personal health management.

Access to Schemes

Disability Inclusive Development (DID) project, aimed at empowering individuals affected by leprosy in Bihar, Jharkhand, and Uttar Pradesh, one pivotal aspect is facilitating access to government schemes and entitlements. This section delves into the impact of the DID project in enabling beneficiaries to access key government schemes and services, thereby fostering socio-economic empowerment.

Table 23: Access to Welfare Schemes – DID State Specific (N=160)

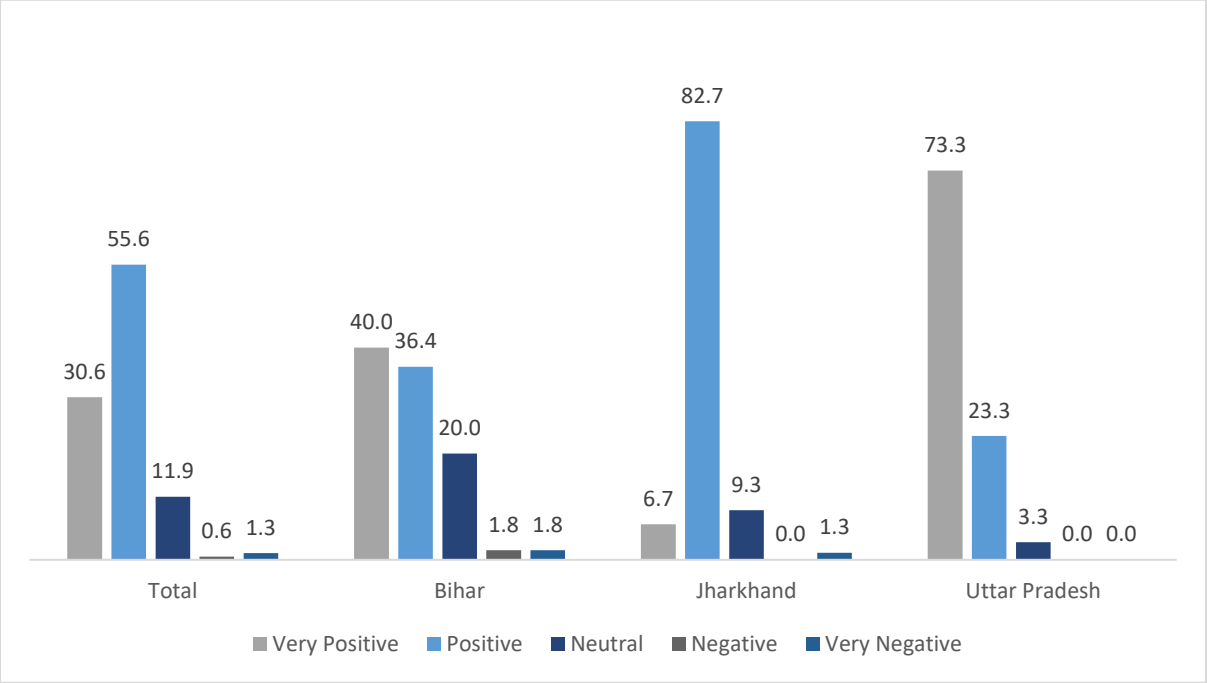
Scheme	Total	Bihar	Jharkhand	Uttar Pradesh
Aadhar Card	26.3%	40.0%	21.3%	13.3%
Ration Card	28.1%	45.5%	22.7%	10.0%
Disability Certificate	81.3%	94.5%	82.7%	53.3%
Unique disability identity (UDID) card	3.1%	7.3%	0.0%	3.3%
Disability Pension	73.1%	87.3%	80.0%	30.0%
MNREGA Job Card	6.9%	14.5%	0.0%	10.0%
Rail Pass	8.8%	16.4%	1.3%	13.3%
Bus Pass	12.5%	23.6%	0.0%	23.3%
Toilet Services	11.3%	27.3%	2.7%	3.3%
Pradhan Mantri Awas Yojna	6.9%	16.4%	0.0%	6.7%
Assistive Devices	12.5%	10.9%	10.7%	20.0%
Bank Loan	2.5%	7.3%	0.0%	0.0%
Social Security (e.g. old age, widowhood)	2.5%	5.5%	0.0%	3.3%
Any Education scheme/service	7.5%	3.6%	1.3%	30.0%
Any Health scheme/service	38.8%	9.1%	58.7%	43.3%
Any Livelihood scheme/service	13.1%	3.6%	17.3%	20.0%
Disability Friendly Voter Booths	8.1%	10.9%	1.3%	20.0%
Assistance at government offices	8.8%	12.7%	0.0%	23.3%

Key Insights:

1. Disability Certificate: The vast majority of beneficiaries (81.3%) have successfully obtained disability certificates, facilitating access to various disability-related benefits and services.
2. Disability Pension: A significant portion (73.1%) of beneficiaries have accessed disability pensions, providing essential financial support to individuals affected by leprosy.
3. Health Services: While only a small percentage in Bihar (9.1%) have accessed health services, the figures soar in Jharkhand (58.7%) and Uttar Pradesh (43.3%), reflecting the project's impact on improving healthcare access.
4. The linkage with a number of other relevant schemes needs to be strengthened. E.g. only around 26% and 28% have Aadhar and Ration cards respectively.

Life & Well Being

Figure 22: DID Impacted Overall Life & Well Being - State Wise (In Percentage, N=160)



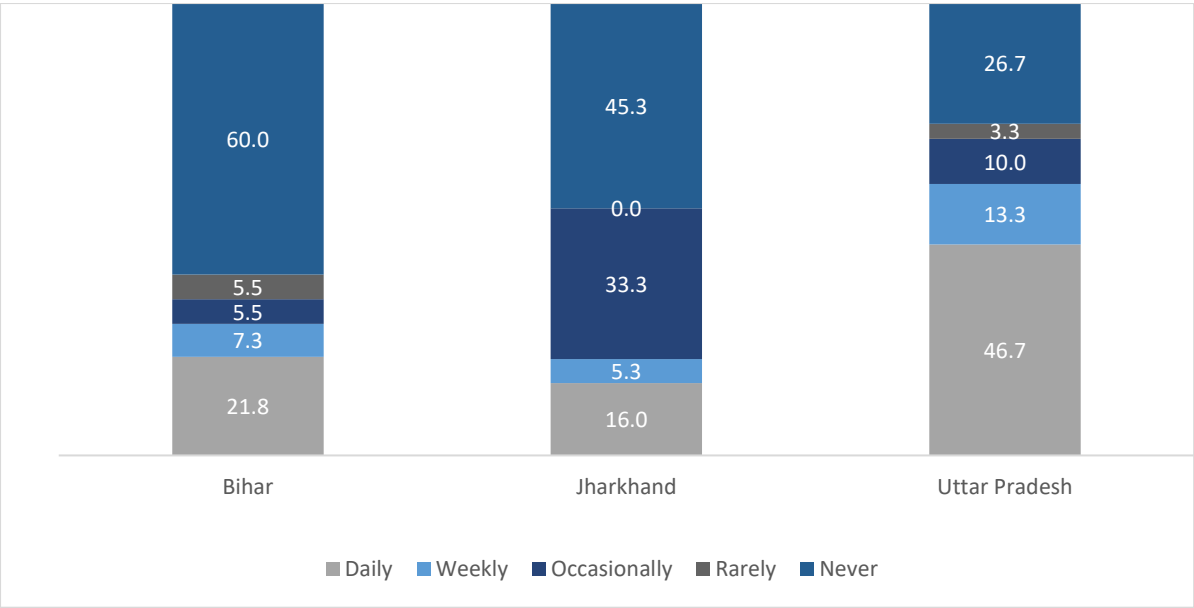
Key Observations:

1. Bihar: Beneficiaries in Bihar express predominantly positive views, with 40.0% describing their overall life and well-being as very positive and 36.4% as positive. This reflects a generally optimistic outlook among beneficiaries in the state.
2. Jharkhand: The responses from Jharkhand present a contrasting picture, with only 6.7% describing their overall life and well-being as very positive. However, the majority (82.7%) perceive their life and well-being positively, indicating a strong sense of satisfaction.
3. Uttar Pradesh: Uttar Pradesh stands out with 73.3% of beneficiaries describing their overall life and well-being as very positive, reflecting a high level of contentment and fulfilment among beneficiaries in the state.

Mobility Assistive Devices:

The data underscores the importance of access to assistive devices in promoting mobility and independence among individuals affected by leprosy. While some beneficiaries demonstrate consistent utilization, others may face barriers or challenges in accessing and using these devices regularly.

Figure 23: Frequency of Usage of DID Assistive Devices - State Specific (In Percentage, N=160)



Key Observations:

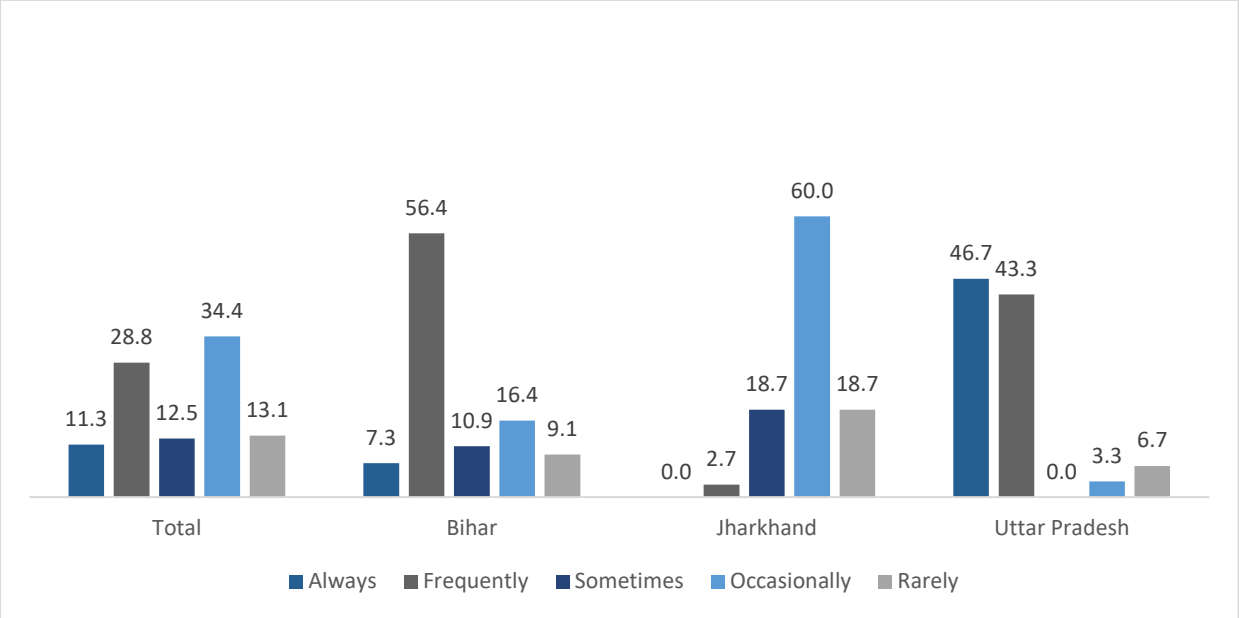
1. Bihar: Beneficiaries in Bihar exhibit varying levels of utilization, with a significant proportion (60.0%) reporting never using assistive devices. However, those who do use them demonstrate a relatively consistent frequency, with 21.8% using them daily.
2. Jharkhand: In Jharkhand, a smaller percentage of beneficiaries (45.3%) report never using assistive devices. However, the frequency of use varies, with 16.0% using them daily and a considerable proportion (33.3%) using them occasionally.
3. Uttar Pradesh: Uttar Pradesh presents a contrasting picture, with a lower percentage (26.7%) of beneficiaries reporting never using assistive devices. A majority (46.7%) use them daily, indicating a high reliance on these devices for mobility and accessibility.

.

Social Participation

Social participation is vital for fostering inclusion and community engagement among individuals affected by leprosy.

Figure 24: DID Beneficiary Frequency in Community Events – State Specific (In Percentage, N=160)

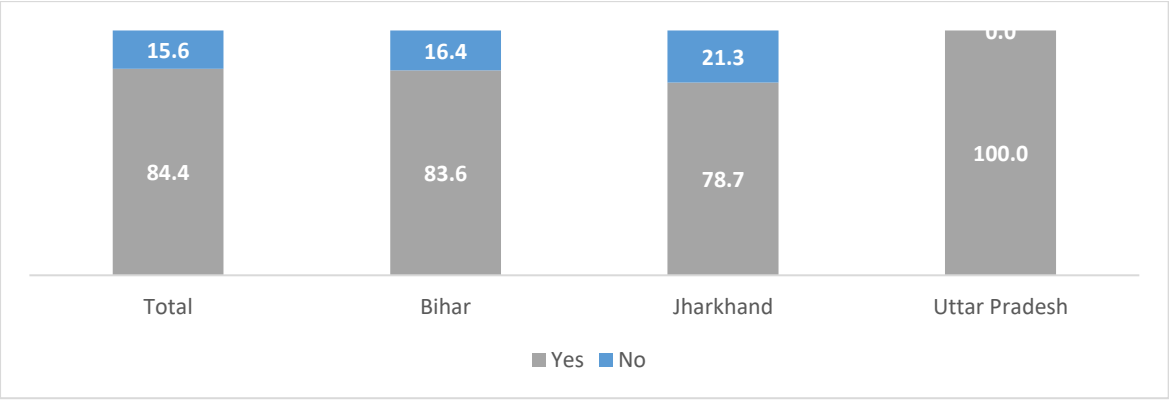


The data underscores the importance of social participation in fostering inclusion and community cohesion among individuals affected by leprosy. Regular engagement in community activities not only enhances social networks but also promotes a sense of belonging and well-being.

Community Support:

Social support from the community plays a crucial role in the well-being and empowerment of individuals affected by leprosy. This section examines the beneficiaries' perception of an increase in social support from the community across Bihar, Jharkhand, and Uttar Pradesh, shedding light on the evolving dynamics of community inclusion and support.

Figure 25: Experienced increased social support from community– DID State Specific (In Percentage, N=160)



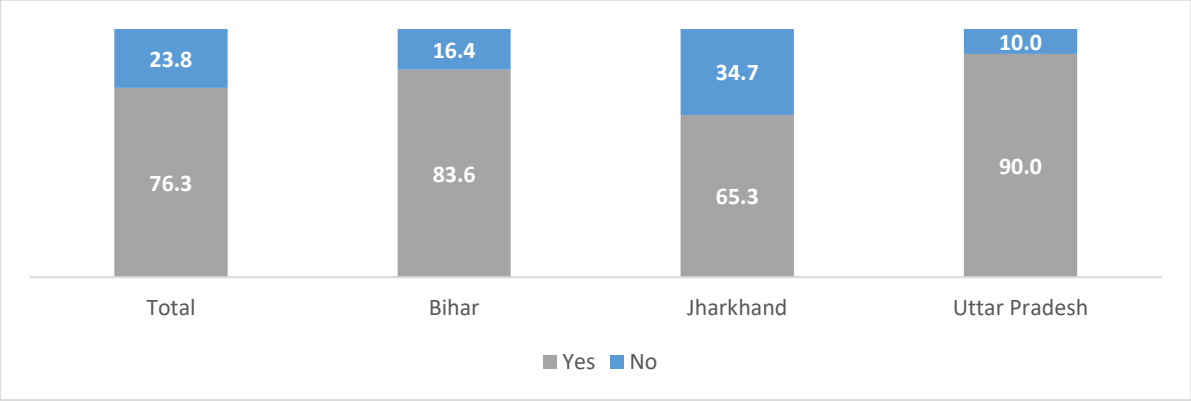
Key Observations:

1. Bihar: Beneficiaries in Bihar overwhelmingly perceive an increase in social support from the community, with 83.6% acknowledging a positive shift. This reflects a strong sense of community cohesion and solidarity among beneficiaries in the state.
2. Jharkhand: Jharkhand presents a similar picture, with the majority (78.7%) of beneficiaries experiencing an increase in social support from the community. This indicates a growing recognition and acceptance of individuals affected by leprosy within the community.
3. Uttar Pradesh: Uttar Pradesh stands out with 100% of beneficiaries acknowledging an increase in social support from the community. This underscores the profound impact of community-based initiatives and awareness efforts in fostering empathy and support among community members.

Community Development

The acquisition of skills and knowledge through support programmes can empower individuals to become catalysts for positive change within their communities. This section explores the involvement of beneficiaries in community development initiatives or projects across Bihar, Jharkhand, and Uttar Pradesh, highlighting their role as active agents of change.

Figure 26: DID beneficiary involvement in Community Development Initiatives – State Specific (In percentage, N=160)



Key Observations:

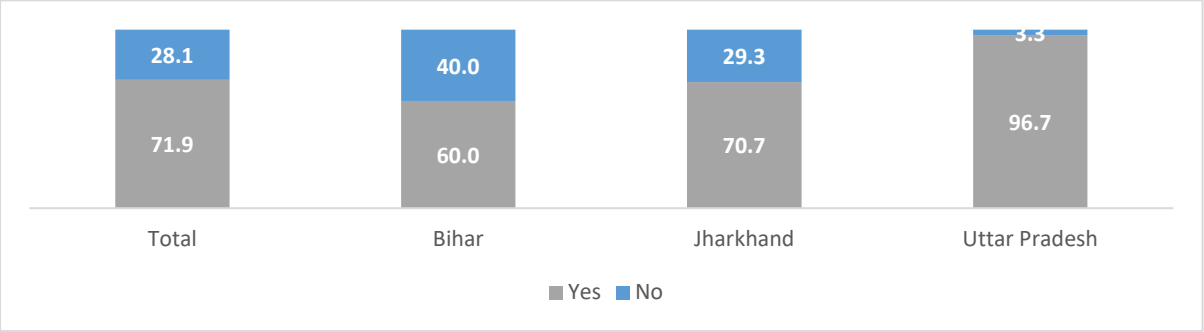
1. Bihar: The majority of beneficiaries in Bihar (83.6%) actively engage in community development initiatives or projects, leveraging their newfound skills and knowledge to drive positive change. This reflects a strong commitment to community improvement and empowerment.
2. Jharkhand: Jharkhand presents a similar trend, with 65.3% of beneficiaries participating in community development initiatives. While slightly lower than Bihar, this still signifies a substantial involvement in driving grassroots change and development.
3. Uttar Pradesh: Uttar Pradesh stands out with 90.0% of beneficiaries actively involved in community development initiatives. This high level of engagement underscores the transformative impact of skills and knowledge gained through support programmes on community development efforts.

Economic Impact

Improved Livelihood

Enhancing livelihood opportunities is a cornerstone of inclusive development initiatives. The data underscores the pivotal role of the project in promoting economic empowerment and livelihood sustainability among beneficiaries. Access to income-generating opportunities not only improves financial well-being but also enhances overall resilience and quality of life.

Figure 27: DID Project helped in increasing household income – State Specific (In Percentage, N=160)



Key Observations Variations:

1. Bihar: A substantial majority of beneficiaries in Bihar (60.0%) report that the project has helped in generating additional income or improving livelihoods. This underscores the project's effectiveness in fostering economic empowerment and enhancing livelihood opportunities within the state.
2. Jharkhand: In Jharkhand, 70.7% of beneficiaries acknowledge the project's positive impact on income generation and livelihood improvement. Despite slightly lower rates compared to Bihar, this still reflects a notable contribution to economic empowerment.
3. Uttar Pradesh: Uttar Pradesh stands out with 96.7% of beneficiaries experiencing an improvement in income generation or livelihoods as a result of the project. This high success rate highlights the project's transformative impact on enhancing economic opportunities and livelihood sustainability.

"Knowledge gained through participation is as crucial as the monetary benefits we receive." – Beneficiary, FGD

Increased Income

Table 24: Increase in Monthly Income in DID Geographies (In Percentage)

Increase in Monthly Income	Total	Bihar	Jharkhand	Uttar Pradesh
No Change	26.9	40.0	26.7	3.3
100-500	30.0	20.0	26.7	56.7
500-1000	16.3	0.0	24.0	26.7
1000-2000	9.4	7.3	12.0	6.7
2000-5000	10.0	25.5	1.3	3.3
5000-10000	5.6	5.5	6.7	3.3
Over 10000	1.9	1.8	2.7	0.0

Key Observations:

1. Bihar: Among those who experienced an increase, a notable percentage (25.5%) reported an increase in the range of 2000-5000 rupees, highlighting substantial improvements in income levels.
2. Jharkhand: In Jharkhand, a substantial percentage (26.7%) of beneficiaries reported an increase in income ranging from 100-500 rupees, indicating moderate improvements in financial well-being. However, a considerable proportion (24.0%) experienced an increase in the 500-1000 rupees range, reflecting notable strides in income enhancement.
3. Uttar Pradesh: Uttar Pradesh stands out with a percentage (56.7%) of beneficiaries experiencing an increase in income ranging from 100-500 rupees. Additionally, a notable proportion (26.7%) reported an increase in the 500-1000 rupees range, showcasing substantial improvements in economic opportunities.

Management of Finances

Effective financial management is essential for achieving economic stability and resilience. This section delves into the management of finances among DID. Financial management practices empower individuals to make informed decisions and build economic resilience. Access to financial education and formal banking services plays a crucial role in fostering financial literacy and protecting beneficiaries from exploitative practices.

Table 25: Financial Practices in DID Geographies (In Percentage)

Financial Practices	Total	Bihar	Jharkhand	Uttar Pradesh
N	160	55	75	30
Save a portion of my income regularly	85.6%	70.9%	97.3%	83.3%
Access to financial education	19.4%	14.5%	9.3%	53.3%
Confidence in making financial decisions	37.5%	12.7%	44.0%	66.7%
Establish an emergency fund	27.5%	25.5%	36.0%	10.0%
Community-based financial support system	29.4%	16.4%	33.3%	43.3%
Protected me from exploitative financial practices	3.1%	1.8%	2.7%	6.7%
Access to formal banking services	10.6%	3.6%	1.3%	46.7%

Key Observations:

1. Savings Habits: Most beneficiaries across all states demonstrate a strong savings habit, with particularly high rates in Jharkhand (97.3%) and Uttar Pradesh (83.3%). This indicates a proactive approach towards financial planning and security.
2. Access to Financial Education: Uttar Pradesh leads in providing access to financial education, with 53.3% of beneficiaries benefiting from such programmes. However, there is room for improvement in Bihar (14.5%) and Jharkhand (9.3%), highlighting the need for expanded educational initiatives.
3. Confidence in Financial Decision-Making: Uttar Pradesh exhibits the highest level of confidence in making financial decisions, with 66.7% of beneficiaries expressing confidence. Bihar (12.7%) and Jharkhand (44%) show moderate levels of confidence, indicating varying degrees of financial literacy and empowerment.
4. Access to Formal Banking Services: Uttar Pradesh leads in access to formal banking services, with 46.7% of beneficiaries utilizing such services. Bihar (3.6%) and Jharkhand (1.3%) show poor rates, suggesting potential barriers to financial inclusion.

5. Protection from Exploitative Financial Practices: A small percentage of beneficiaries across states report protection from exploitative financial practices. Notably, Uttar Pradesh (6.7%) demonstrates higher levels of protection, potentially due to improved access to formal banking services.

Addressing disparities in access to financial education and formal banking services remains critical. Strengthening community-based financial support systems and promoting microfinance opportunities can further enhance financial inclusion and empowerment. Effective financial management is integral to achieving economic stability and resilience among DID beneficiaries. By promoting savings habits, enhancing access to financial education, and fostering confidence in financial decision-making, the project contributes to building financially empowered communities across Bihar, Jharkhand, and Uttar Pradesh.

Outcome Harvesting

Table 26: Outcome Harvesting - Disability Inclusive Development (DID)

S. No.	Project	Key Outcome	Evidence
1	Disability Inclusive Development	***Economic Empowerment and Livelihood Improvement***	71.9% of beneficiaries reported an increase in income or improvement in livelihoods. Beneficiaries (85.6%) saved a portion of their income regularly, demonstrating enhanced financial management skills and stability. Access to government schemes and services, such as disability pensions (73.1%) provided crucial financial support to beneficiaries.
2		***Social Inclusion and Community Participation***	Beneficiaries (84.4%) noted an increase in social support from the community, highlighting improved social inclusion and acceptance. 76.3% of beneficiaries have become actively involved in community development initiatives or projects, showcasing their growing sense of ownership and agency. 40% of beneficiaries reporting either frequent or always involvement in community activities since participating in the project.
3		***Enhanced Self-Care Practices and Well-being***	Self-care practices improved with 67.5% reporting regular engagement in self-care activities. Beneficiaries (86.3%) expressed a very positive or positive outlook on their overall life and well-being, reflecting a tangible shift towards optimism and resilience

Conclusions

The Disability Inclusive Development (DID) project, spearheaded by NLR India's Empowering Persons with Disability (PWD) initiative, has emerged as a beacon of change in Bihar, Jharkhand, and Uttar Pradesh. Through its community-based rehabilitation efforts and strategic collaborations, the project has made notable strides in promoting disability-inclusive development and empowering individuals affected by leprosy.

Key achievements of the DID project include:

1. Enhanced Self-Care Practices: Beneficiaries have demonstrated notable improvements in self-care methods, leading to better management of their health and well-being.
2. Promotion of Disability Empowerment: Increased awareness of rights and entitlements, coupled with active participation in community-based institutions, has empowered beneficiaries to advocate for themselves.
3. Improved Access to Leprosy Services: Through collaborative efforts with government health systems, the project has facilitated better access to leprosy services, particularly in urban areas.
4. Community Acceptance and Support: The project has garnered widespread acceptability and support from both government health systems and the community, fostering a sense of ownership and participation among stakeholders.

Recommendations

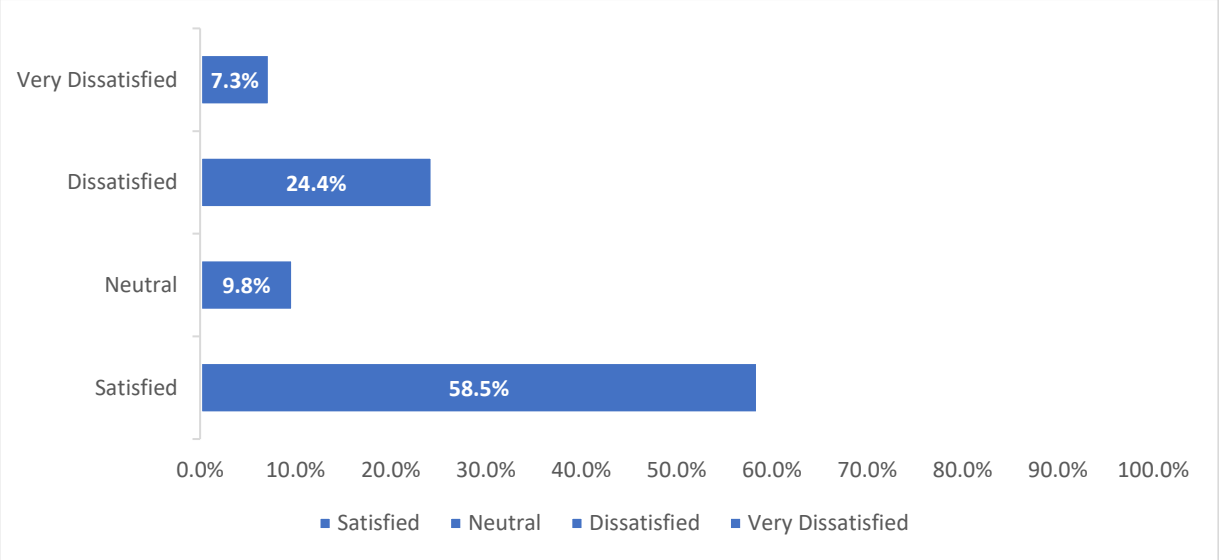
- Replicate community-based disability inclusive development (DID) for persons with disabilities for comprehensive support. NLRIF advocated model may be implemented.
- Establish coordination between different departments like Empowerment of Persons with Disabilities (EPWD), Social Welfare, Livelihood, Panchayati Raj and Health.
- Local CBOs/ NGOs may be mobilized by DEPWD to lead the implementation.
- Promote collectivization in the form of self-help groups, selfcare groups, organizations of persons with disabilities (OPD) etc.
- Empower the affected persons with disabilities about their entitled services including different schemes and assistive devices.
- Establish mechanism for improving access to services and schemes e.g. through a resource directory and digital applications.
- Develop peer supporters for stronger linkage with the community.
- Selfcare and psycho-social support may be integrated with DID.
- Mobilize support for livelihood through inter-departmental linkage e.g. Krishi Vikas Kendra (KVK) and State Rural Livelihood Mission (SRLM).
- Introduce quarterly ADL and IADL assessment.
- GIS mapping of the persons with disabilities.

Urban Leprosy Programme: Specific Insights

Specific Insights - Urban Leprosy

The Urban Leprosy Programme in West Bengal, implemented through Urban Primary Health Centres (UPHCs), strives to improve leprosy services, community engagement, and overall health outcomes.

Figure 28: Satisfaction with UPHC Services: ULEP (N=41)

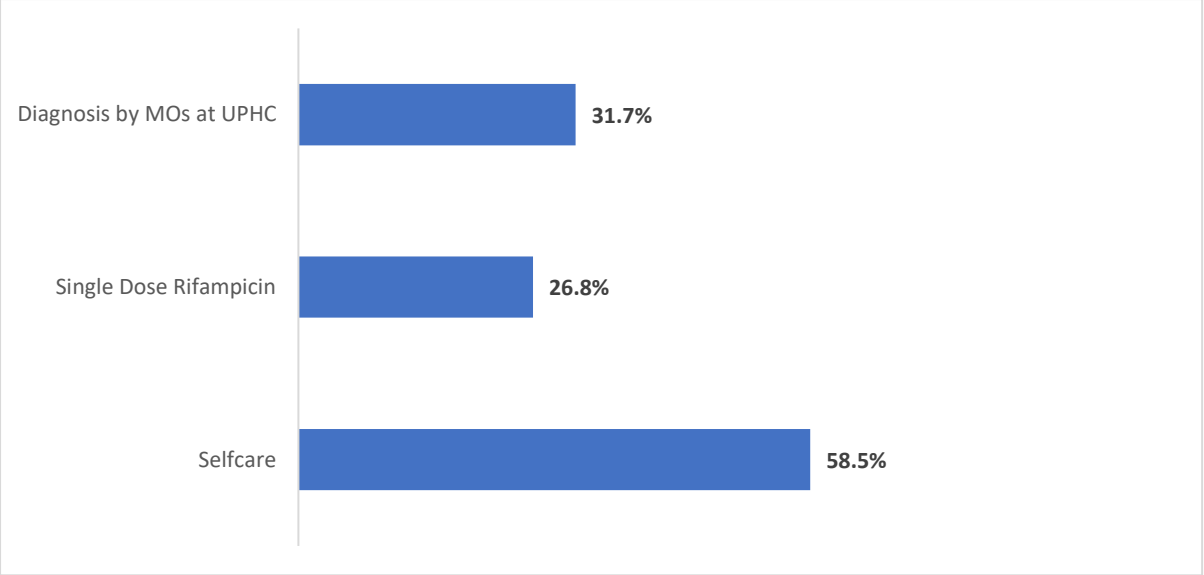


Key Observations:

- Referral Process Engagement: 56.1% of beneficiaries were referred by frontline health workers to Urban Primary Health Centres (UPHCs) for leprosy services, indicating active engagement. However, there is room for improvement in enhancing the referral process and increasing awareness about available services.
- Mixed Satisfaction with Services: While 58.5% expressed satisfaction with leprosy services at UPHCs, 31.7% reported dissatisfaction. Addressing concerns of dissatisfied individuals through regular feedback sessions and strengthening communication channels between providers and beneficiaries is crucial for better service delivery.

"Early detection and treatment are pivotal, and various government initiatives are in place to address leprosy. The numbers of beneficiaries have increased in the past few years" - Government Official, IDI

Figure 29: Leprosy Services Accessed by Beneficiaries at UPHC (N=41)



Key Observations:

- Almost 68% of the leprosy cases are being diagnosed at higher health facilities and referred to UPHC.
- Limited SDR Uptake: Only 26.8% of beneficiaries reported their family and contacts received Single Dose Rifampicin (SDR) through the programme, suggesting a potential gap in awareness or accessibility to preventive measures. Targeted awareness campaigns can contribute to increased acceptance and uptake of preventive measures.
- Active Engagement in Self-Care Training: A substantial 58.5% of beneficiaries actively engaged in self-care training, showcasing a commitment to empowering individuals with knowledge and skills for effective self-management, a core objective of the programme.

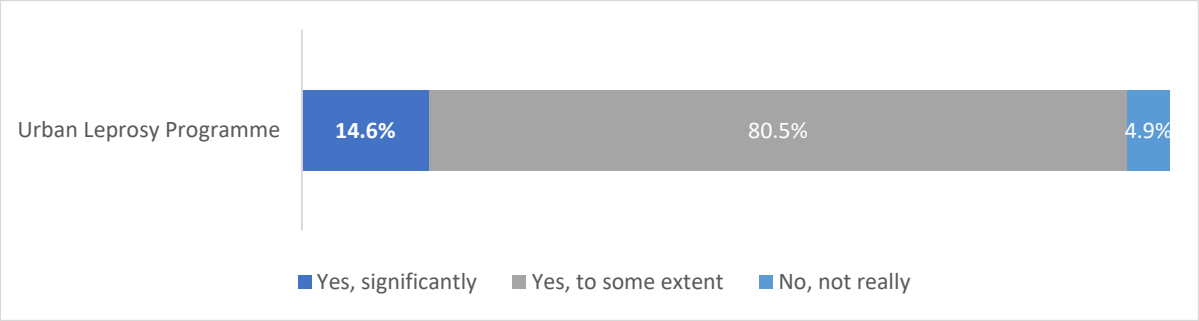
The programme's emphasis on self-care training, diagnosis, treatment, and preventive measures reflects a holistic approach. Strengthening follow-up processes by frontline workers ensures ongoing support, monitoring, and timely intervention, contributing to the continuity of care and overall programme effectiveness. The ULEP plays a pivotal role in community well-being through UPHCs. Strategic improvements and continuous evaluation, along with targeted awareness initiatives, will further enhance the programme's effectiveness in providing holistic support to individuals affected by leprosy in urban settings.

Perceived Impact

Awareness and Selfcare Practice

The Urban Leprosy Programme in West Bengal, implemented through Urban Primary Health Centres (UPHCs), not only aims to enhance leprosy services but also strives to improve knowledge and awareness about leprosy among beneficiaries.

Figure 30: Project Involvement Improved Leprosy Knowledge – Urban Leprosy (N=41)

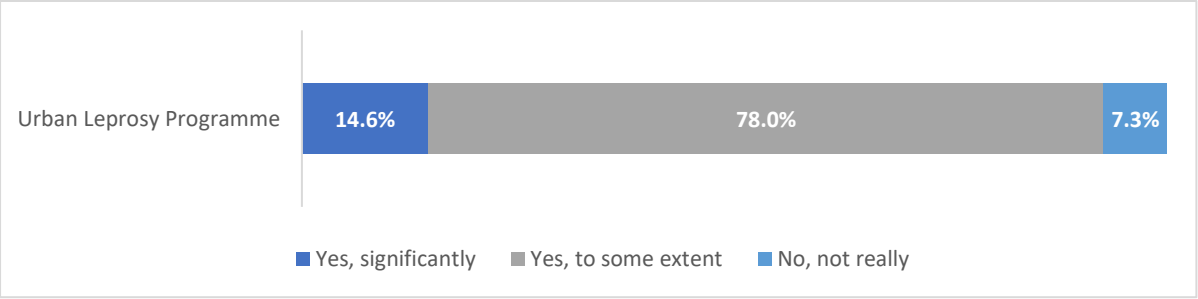


"Sharing information within our community is crucial. We must actively participate in programmes and ensure that every member is well-informed about health initiatives."
– Community Member, KII

Key Observations:

- Improvement in Leprosy Knowledge: A substantial 80.5% of respondents acknowledged the project's contribution to enhancing their understanding of leprosy to some extent, with 14.6% reporting significant improvement.
- Self-care Practices: Analysis reveals that 78.0% of beneficiaries experienced some level of improvement in self-care practices, with 14.6% reporting a significant increase in understanding.

Figure 31: Improvement in Selfcare Practices – ULEP Project Specific (N=41)

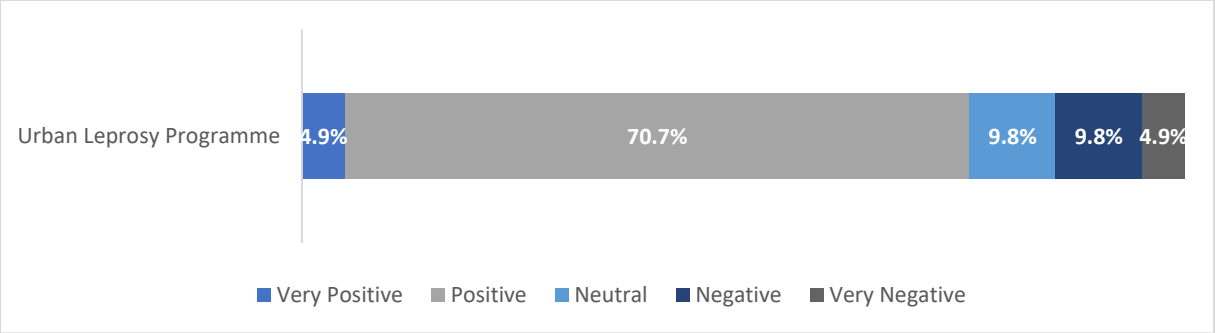


The Urban Leprosy Programme places a strong emphasis on empowering individuals with the knowledge and skills necessary for effective self-management of leprosy. Analysis of data regarding the practice of self-care methods among programme beneficiaries provides insights into the extent to which individuals are engaging in self-care practices.

Life & Well Being

The overarching goal of the Urban Leprosy Programme is to not only enhance leprosy services but also to improve the overall quality of life and well-being of individuals affected by leprosy.

Figure 32: Project Impact on Life & Well-Being (N=41)



Key Observations:

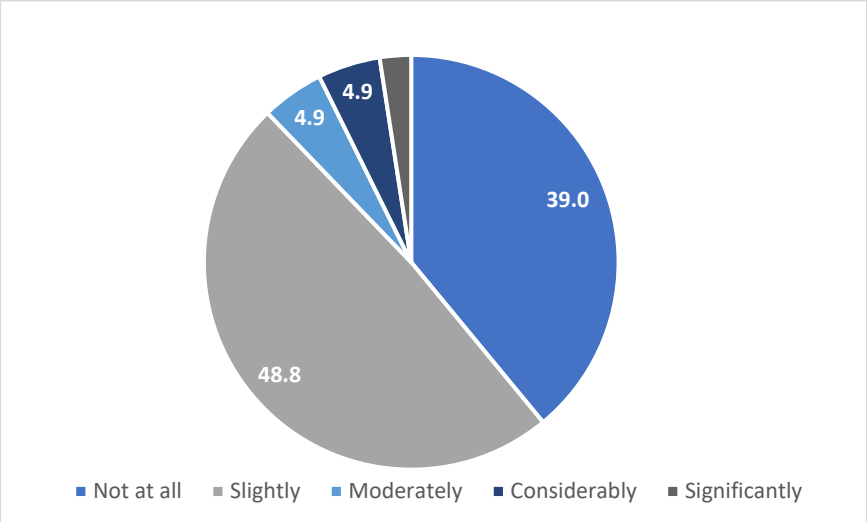
- Positive Impact: 70.7% of respondents reported a positive impact on their lives, with 4.9% indicating a very positive impact.
- Neutral/Negative Impact: 19.6% reported a neutral or negative impact, emphasizing the need for ongoing improvement efforts.

Overall, the data suggests that the Urban Leprosy Programme has made notable strides in positively impacting the lives and well-being of individuals affected by leprosy. By continuing to focus on delivering high-quality, comprehensive services and addressing the evolving needs of beneficiaries, the programme can further enhance its positive impact and contribute to improved health outcomes and quality of life for those it serves.

Social Participation

The Urban Leprosy Programme me not only aims to improve leprosy services but also seeks to foster social inclusion and community engagement among individuals affected by leprosy.

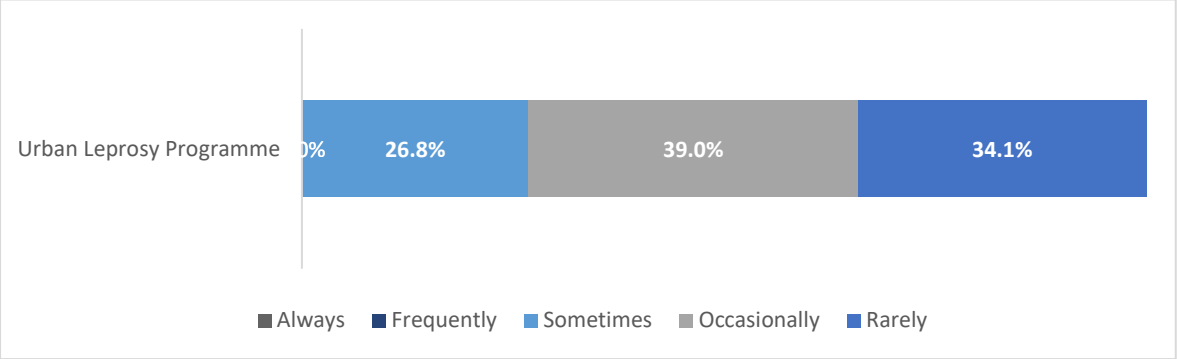
Figure 33: ULEP Implementation increased participation in community events (In Percentage, N=41)



Key Observations:

- Influence on Community Events: While 39.0% reported no impact, 48.8% experienced slight impact, indicating progress but highlighting the need for further community engagement strategies.
- Participation Frequency: A notable proportion rarely (34.1%) or occasionally (39.0%) participate in community events, underlining potential challenges in integration.

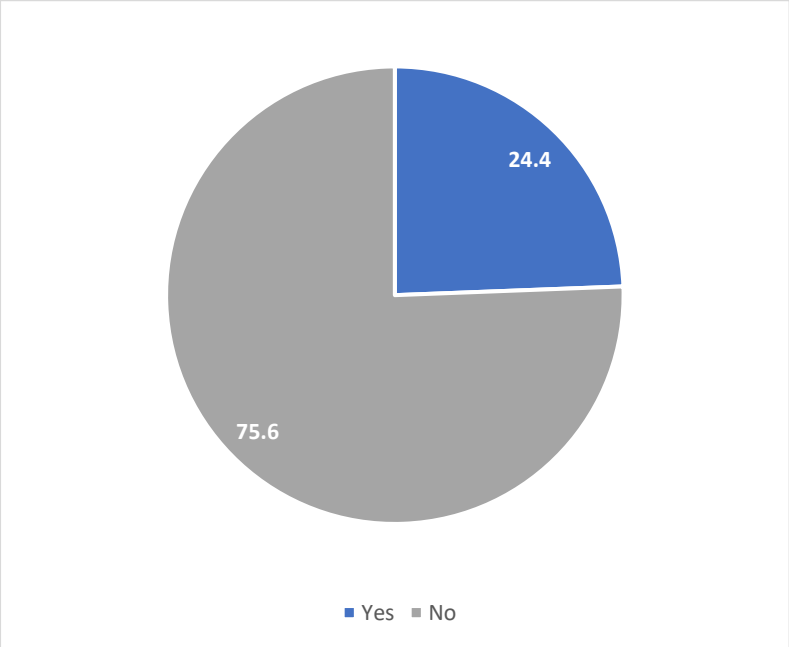
Figure 34: Engagement in Community Events post ULEP implementation (In Percentage, N=41)



Community Support

One of the key objectives of the Urban Leprosy Programme is to promote social inclusion and support for individuals affected by leprosy within their communities. Understanding whether the Programme has succeeded in increasing social support from the community provides valuable insights into its effectiveness in addressing social stigma and fostering acceptance. According to recent survey findings, the majority of respondents reported not noticing an increase in social support from their community following the implementation of the project. Specifically, 75.6% of respondents indicated that they had not observed any change in social support levels.

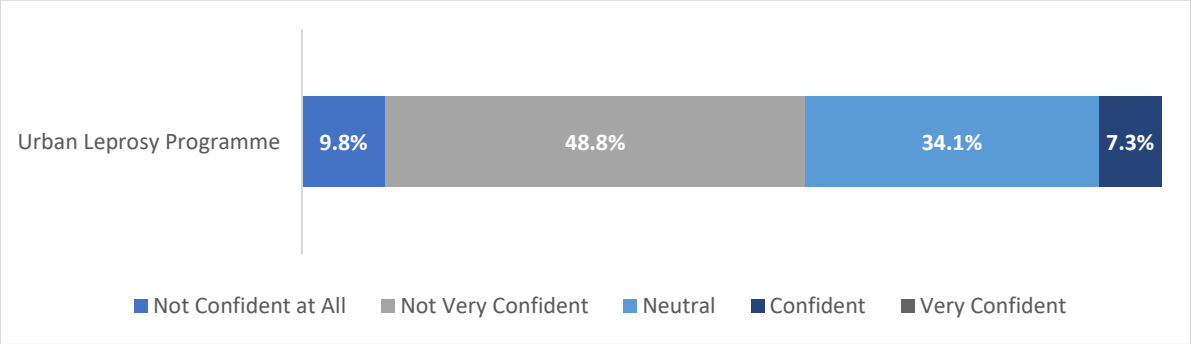
Figure 35: Increase in Community Support post ULEP Implementation (In Percentage, N=41)



Community Involvement:

The majority of respondents expressed varying levels of confidence in participating in community discussions and decision-making processes. A notable proportion of respondents (48.8%) reported not feeling very confident, indicating potential barriers or challenges to active participation.

Figure 36: Confidence in Participation in Community Decision-Making: ULEP (N=41)

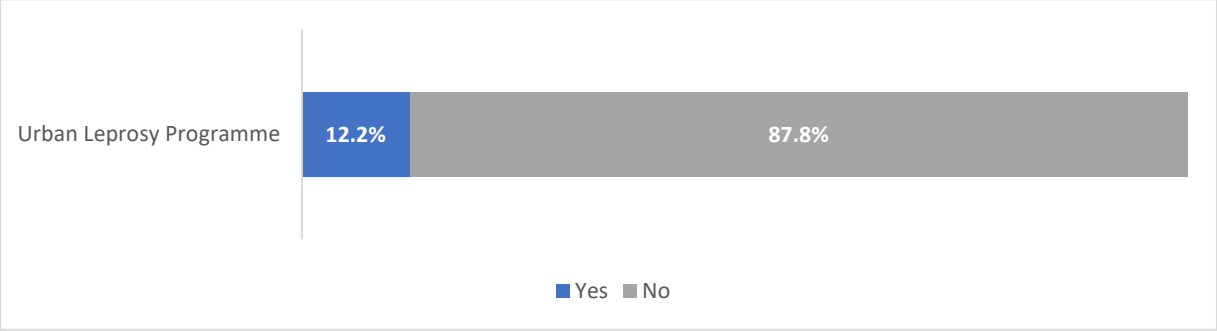


Moving forward, efforts to enhance confidence levels and promote active participation in community activities should be prioritized as part of the broader strategy to promote social inclusion and empowerment among individuals affected by leprosy. By providing opportunities for skill-building, education, and leadership development, the Programme can help empower beneficiaries to actively engage in shaping their communities and advocating for their rights and interests.

Economic Impact

The majority of respondents reported not experiencing an increase in their ability to generate additional income following the implementation of the Programme. Specifically, 87.8% of respondents indicated that they had not been able to incur additional income with the support provided by the Programme.

Figure 37: Perceived Impact on Income Generation (N=41)



While this data suggests that there may be challenges or barriers to economic empowerment among beneficiaries, it's important to recognize that addressing economic vulnerabilities requires holistic and sustained interventions that go beyond direct support.

Key Observation:

- While 12.2% reported increased income generation, the majority (87.8%) did not, suggesting persistent economic vulnerabilities.

Estimates of Income Increase:

Respondents who reported an increase in monthly income provided estimates across various ranges. The majority, 80.5%, fell into the category of "No changes".

Table 27: Increase in Monthly Income – ULEP Specific (N=41)

Increase in Monthly Wages	ULP
No Changes	80.5%
100-500	14.6%
500-1000	2.4%
1000-2000	2.4%
2000-5000	0.0%
5000-10000	0.0%
Over 10000	0.0%

Financial Management:

The majority of respondents reported engaging in various financial practices aimed at enhancing their financial well-being. Notably, 39.0% of respondents indicated that they regularly save a portion of their income, highlighting a commitment to building financial security and resilience.

Table 28: Reported Financial Practices by ULEP Beneficiaries (In Percentage, N=41)

Financial Practices	Percentage
Save a portion of my income regularly	9.8%
Access to financial education	19.5%
Confidence in making financial decisions	22.0%
Establish an emergency fund	19.5%
Community-based financial support system	4.9%
Access microfinance opportunities	2.4%
Protected from exploitative financial practices	0.0%
Access to formal banking services	0.0%

Key Observation:

- Financial Practices: Only 9.8% save regularly, indicating room for improvement in financial literacy and empowerment. However, 22% express confidence in making financial decisions

Overall, while the Urban Leprosy Programme has made notable strides in enhancing awareness, self-care practices, and overall well-being, there are persistent challenges in economic empowerment, social integration, and community support. Continued efforts to address these challenges through targeted interventions and community engagement are essential for maximizing the programme's impact and ensuring holistic support for individuals affected by leprosy.

Outcome Harvesting

Table 29: Outcome Harvesting - Urban Leprosy Programme

S. No.	Project	Key Outcome	Evidence
1	Urban Leprosy Programme	***Improved Health Services and Self-Care***	31.7% of new leprosy cases diagnosed by UPHC Medical Officers showcase rollout of leprosy services by urban primary health centers in urban areas. 80.5% of beneficiaries reported an increase in knowledge about leprosy, reflecting improved awareness and understanding of the disease. 56.1% of beneficiaries referred by frontline health workers to UPHCs, indicating active engagement with healthcare services
2		***Community Engagement and Social Support***	24.4% of beneficiaries reported an increase in social support from their community, highlighting improved acceptance and integration. 48.8% of beneficiaries reported slight impact on social events or community activities, showcasing a moderate level of community engagement. 34.1% of beneficiaries reported occasionally participating in community events, demonstrating some level of involvement in community activities.

Conclusions

The Urban Leprosy Programme has achieved notable progress in tackling the complexities of leprosy in urban West Bengal. Through a multifaceted approach centered on improving services, empowering affected individuals, and engaging communities, the programme has delivered tangible benefits to various stakeholders.

Key achievements include:

1. Involvement of urban primary health centers in delivery of leprosy services. In around 3 years, almost one-third of the new leprosy cases are being diagnosed by the UPHC.
2. UPHCs are also guiding the affected on selfcare and administering SDR to the eligible contacts.
3. Around one fourth (24.4%) of beneficiaries reported an increase in social support from their community, highlighting improved acceptance and integration.

In summary, the Urban Leprosy Programme has made notable strides in enhancing leprosy services, empowering affected individuals, and fostering community engagement in urban West Bengal. While progress has been achieved, ongoing efforts are essential for greater number of new cases to be referred and diagnosed at UPHC compared to higher health facilities.

Recommendations

1. Strengthen leprosy service delivery through UPHC.
2. Increase referral of suspect cases to UPHC for diagnosis and treatment.
3. SDR needs to be administered to eligible contacts of all the diagnosed cases.
4. DPMR services need to be provided to all the affected persons.
5. Involvement of UPHC

Call Centre Project: Specific Insights

Call Center Project Specific Insights

The Vikalp Project in Rajasthan, operating through a call centre, employs a comprehensive strategy to support individuals in managing leprosy. The project involves proactive engagement through calls, raising awareness, providing information on self-care, and conducting regular follow-ups.

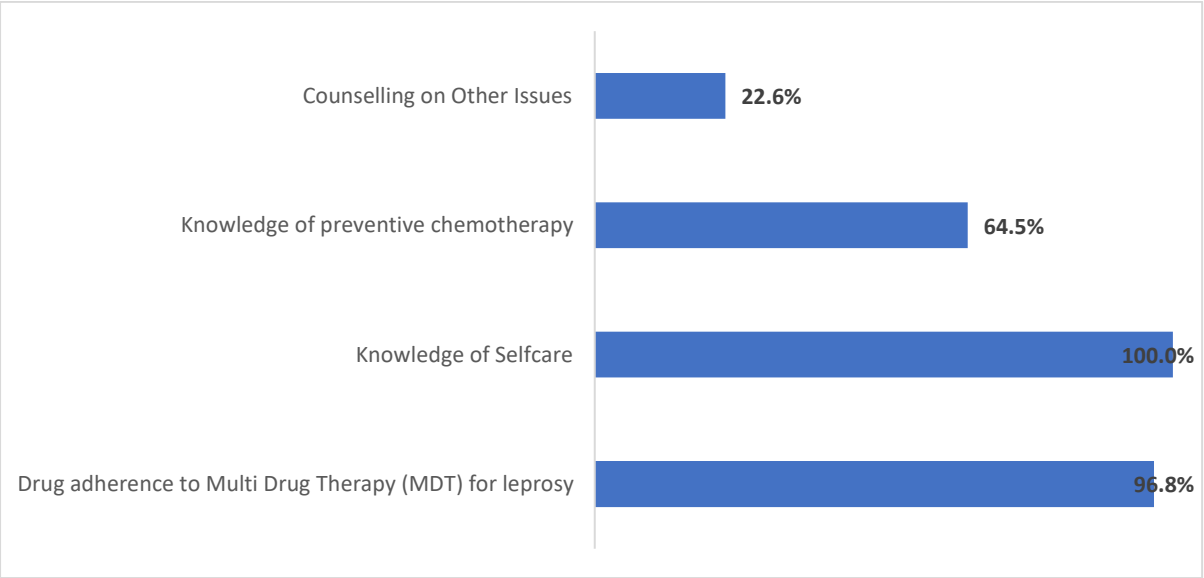
Project Reach

According to the survey results, 100% of respondents reported receiving first time as well as follow up calls from the call centre as part of the Vikalp Project. This high reception rate indicates widespread engagement and participation among individuals undergoing leprosy treatment, reflecting the project's successful outreach efforts and the effectiveness of its communication strategies.

Collaboration

100% of respondents reported collaboration between the call centre and District Leprosy Staff (DLS) for case management and follow-ups as part of the Vikalp Project. This indicates a strong partnership and coordination between the project's call centre and local healthcare providers responsible for overseeing leprosy cases within the community.

Figure 38: Services Accessed by Beneficiaries – VIKALP (N=31)



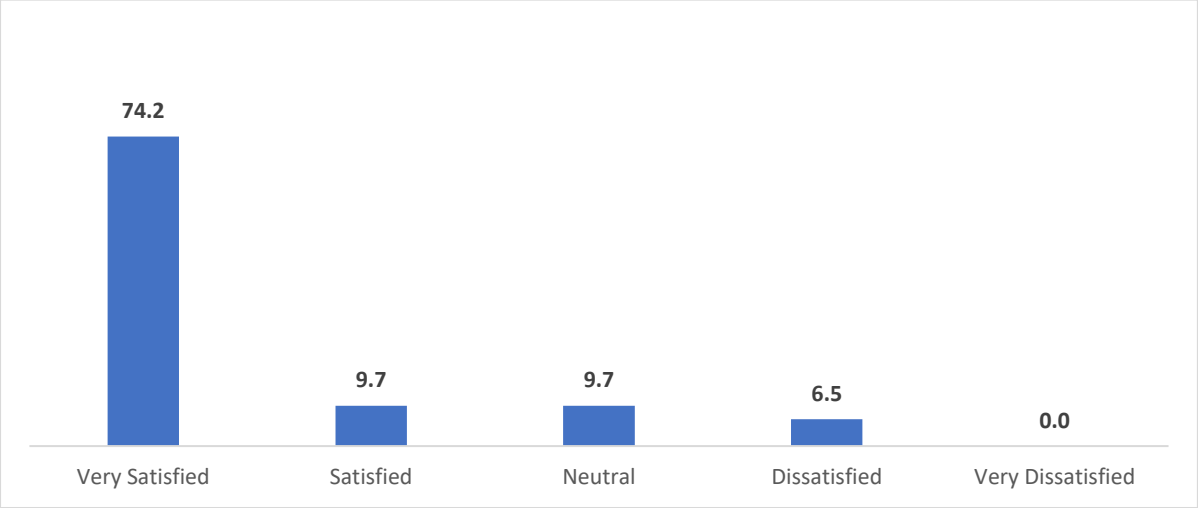
Key Observations:

1. **Drug Adherence to Multi-Drug Therapy (MDT) for Leprosy:** A significant proportion (96.8%) of respondents reported improvement in drug adherence to MDT, reflecting the project's success in promoting adherence to prescribed treatment regimens. This aligns with the project's objective of ensuring effective management of leprosy cases and reducing the risk of treatment failure or relapse.
2. **Knowledge of Self-care Practices:** All respondents (100.0%) reported receiving support for self-care practices through the project. This highlights the project's emphasis on empowering individuals with the knowledge and skills needed for effective self-management, contributing to improved treatment outcomes and overall well-being.
3. **Knowledge on Preventive Chemotherapy:** A majority (64.5%) of respondents reported receiving knowledge on preventive chemotherapy, indicating the project's efforts to prevent the spread of

leprosy within communities by targeting household contacts of new cases. This reflects the project's commitment to implementing preventive measures and reducing the transmission of the disease.

4. **Counselling on other issues:** While a smaller percentage (22.6%) of respondents reported receiving counselling on leprosy-related issues, this aspect still represents a valuable component of the project's services. Counselling plays a crucial role in addressing misconceptions, providing emotional support, and facilitating informed decision-making among individuals affected by leprosy.

Figure 39: Satisfaction Level Among Call Centre Beneficiaries (N=31)



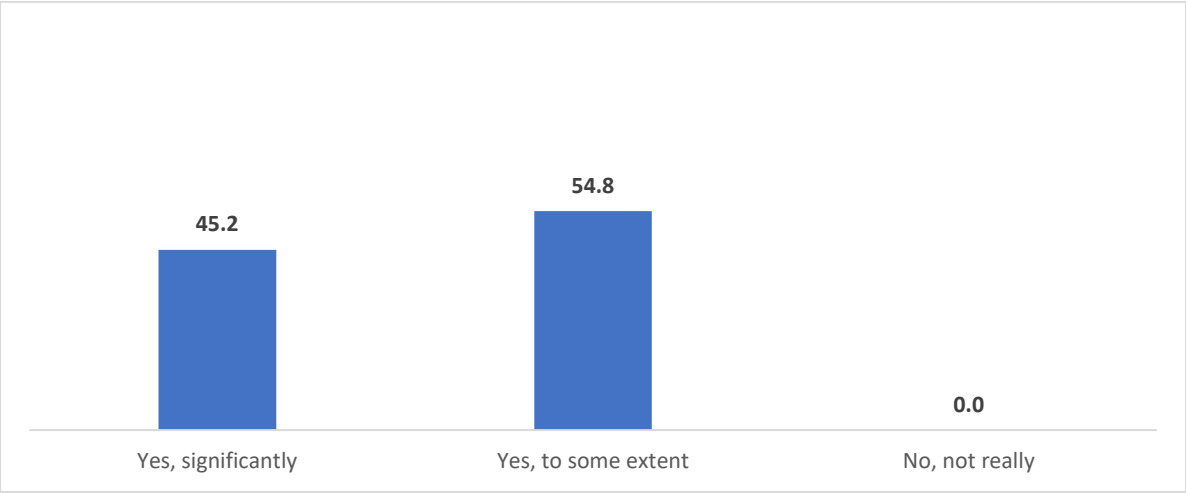
The survey findings indicate high levels of satisfaction among respondents regarding the services provided by the Vikalp Project's call centre. Specifically, 74.2% of respondents reported being very satisfied, while an additional 9.7% reported being satisfied.

The high satisfaction levels suggest that the project has successfully established a supportive and responsive environment, where patients feel valued and well-supported throughout their treatment journey. The project's emphasis on regular communication, education, and guidance, as well as its collaborative approach involving district leprosy staff, likely contributes to the high satisfaction reported by respondents. By offering personalized and timely assistance, the call centre plays a crucial role in enhancing the overall patient experience and promoting positive treatment outcomes.

Perceived Impact

Selfcare Awareness

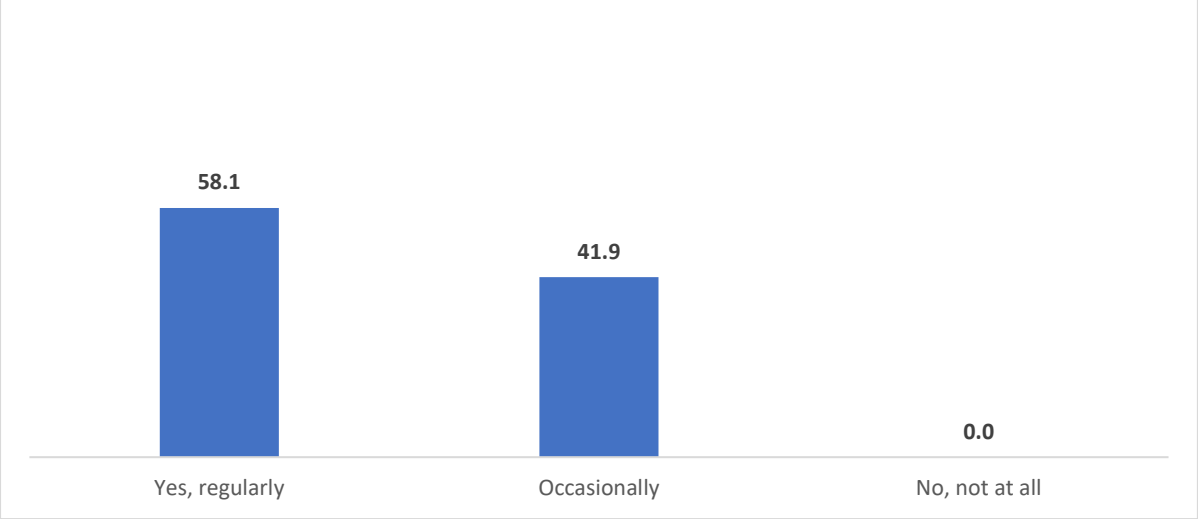
Figure 40: Call Centre Project Impact on Selfcare Awareness (in Percentage, N=31)



Survey findings from the Vikalp Project reveal a notable improvement in self-care knowledge among participants. 45.2% reported a notable enhancement, while 54.8% indicated some improvement. Encouragingly, no respondents reported no improvement, showcasing the project's positive influence on self-care awareness. This aligns with the project's goal of empowering individuals to manage their condition effectively through education and information dissemination.

Selfcare Practice

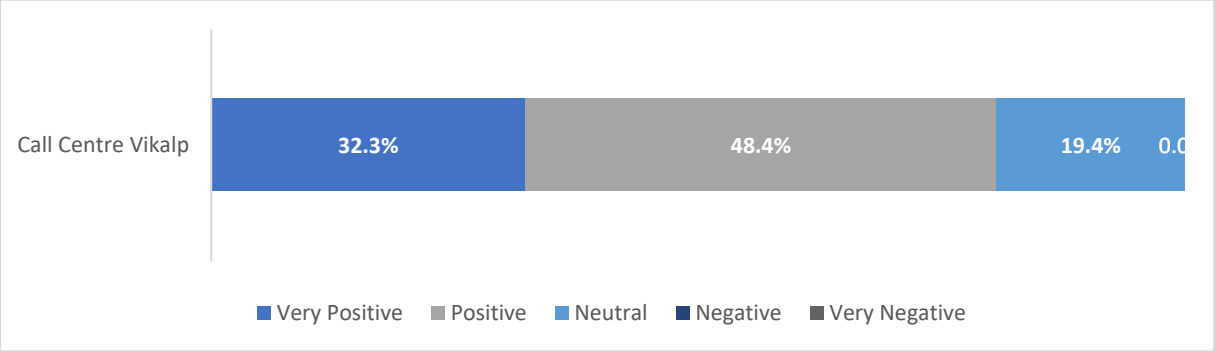
Figure 41: Improvement in Selfcare Practices – Call Centre Project (In Percentage, N=31)



The Vikalp Project's integrated approach has led to a high percentage of respondents (58.1%) practicing self-care methods regularly, with 41.9% practicing occasionally. Notably, no participants reported not practicing self-care at all. This reflects the project's success in promoting self-care adoption among those undergoing leprosy treatment, emphasizing education and support for effective implementation.

Life & Well Being

Figure 42: Project Impact on Life & Well-Being – Vikalp (N=31)



Evaluation of life and well-being perceptions among leprosy-affected individuals participating in the Vikalp Project indicates predominantly positive impacts. 32.3% described the impact as very positive, and 48.4% as positive, with no negative perceptions reported. This underscores the project's effectiveness in addressing participants' needs, improving treatment adherence, and enhancing overall quality of life. The absence of negative perceptions highlights the project's success in fostering a supportive environment for affected individuals, contributing to holistic well-being.

Outcome Harvesting

Table 30: Outcome Harvesting - Vikalp

S. No.	Project	Key Outcome	Evidence
1	Call Center Project - Vikalp	***Empowerment through knowledge on drug adherence, Self-Care and preventive chemotherapy***	96.8% of respondents reported improvement in drug adherence to MDT. 100% of respondents gained knowledge on self-care practices. 58.1% of respondents reported practicing self-care methods regularly, with an additional 41.9% practicing them occasionally. 64.5% of respondents understood the importance of preventive chemotherapy to their family members.
2		***Strengthening Collaboration for Comprehensive Care***	100% of respondents reported collaboration between the call centre and District Leprosy Staff (DLS) for case management and follow-ups. Survey findings indicate high levels of satisfaction with the collaborative approach, with 77.4% of respondents considering it very helpful and an additional 22.6% considering it helpful for receiving follow-up services. All respondents received regular calls from the call centre, highlighting effective communication and coordination between project components.

Conclusion

The Vikalp Project, utilizing Information & Communication Technology (ICT), has effectively tackled the multifaceted challenges of leprosy management. Its call center-based approach has engaged target groups, improved service access, and fostered stakeholder collaboration. Assessing outcomes reveals notable achievements and areas for enhancement.

1. Impact on Target Groups: The project empowered individuals with leprosy, promoting self-care and enhancing drug adherence, resulting in a 96.8% improvement in drug adherence and 100% uptake of self-care practices among respondents. However, there's a need to emphasize disability empowerment and extend services to urban areas for comprehensive coverage.
2. Acceptability by Government Health System and Community: Collaboration with the government health system and community acceptance underscore the project's relevance. Integration with District Leprosy Staff (DLS) was acknowledged by 100% of respondents, but efforts are needed to strengthen partnerships and community participation.
3. Ease of Implementation and Addressing Challenges: While implementation has been relatively smooth, challenges like consistent follow-ups and resource constraints persist. Streamlining communication and providing capacity-building support can mitigate challenges and enhance effectiveness.
4. Behaviour Change Among Stakeholders: Positive behaviour change was observed among beneficiaries, yet broader community change is needed to reduce stigma. Capacity-building for government health staff can further strengthen engagement.
5. Future Implementation Needs: Expanding services to urban areas, enhancing disability empowerment, and strengthening monitoring mechanisms are key priorities. Incorporating stakeholder feedback and adapting to evolving needs are crucial for long-term relevance and sustainability.

Recommendations

The Vikalp Project can further enhance its impact, promote replication of successful approaches in other regions, and ensure the long-term sustainability of interventions, ultimately contributing to the national goal of eliminating leprosy and improving the well-being of affected individuals and communities.

1. Expand call center services to priority districts of the country as a public private partnership model.
2. Call center may also include follow-up to RFT and migrant cases.
3. Greater confidence of sharing line lists of cases by district leprosy office with the call center.

Limitations of the Study

A considerable dispersion of beneficiaries was observed across states, adversely affecting the productivity of the overall fieldwork. The dispersion also led to a very limited number of adolescent respondents being available for interactions, making the finding for aspects of training sessions like SRH and Life Skills skewed. To mitigate the generalizability limitation, the findings are omitted from the report. In the interior areas, the interview process encountered difficulties as respondents struggled to effectively communicate their responses.

The data collection process for the older projects, namely Selfcare at Colonies and Selfcare at PHC, posed several challenges. The identification of respondents proved to be particularly difficult, with many beneficiaries having migrated or passed away. This was mitigated by selecting an additional buffer from the sampling frame; however, the productivity was affected. In Bihar, the completion of the Selfcare at Colonies sample in selected areas was hindered by sampling frame exhaustion. To address this, coverage was extended to include Selfcare at Colonies beneficiaries in Jharkhand.

Also, to be noted is the fact that participants may provide responses that they believe are socially desirable, leading to response bias. The study may be susceptible to self-reporting bias, especially in cases where participants are aware of the expected outcomes.

It is also important to mention that although the utilization of the Katz Activities of Daily Living (ADL) scale proved valuable in detecting changes in the health status of participants. However, it exhibited limitations in its capacity to capture subtle nuances of improvement during the rehabilitation of older adults. The scale, while sensitive to major shifts, may lack the granularity needed to measure smaller elements of change, potentially underestimating the progress made in certain cases. On a similar note, the Lawton Instrumental Activities of Daily Living (IADL) Scale, though a useful tool, is administered as a self-report test rather than an actual demonstration of functional tasks. This introduced a potential source of bias, as participants may either overestimate or underestimate their ability to perform specific activities. As a result, the findings derived from these scales should be interpreted with caution, considering these inherent limitations in accurately capturing the intricacies of functional changes in older adults.

Annexures

Annexure I: Consent Form

Interview Code	
Date of interview	
District Name	
Village Name	

Introduction and Background

My name is _____, and I represent a research organisation called Athena Infonomics. We are conducting an evaluation on behalf of the NLR India Foundation (NLRIF). NLRIF is a non-profit organization dedicated to creating an inclusive society free from leprosy, allied skin Neglected Tropical Diseases (NTDs), and related disabilities. The foundation has been actively engaged in various states across India, specifically in 130 districts and 150 leprosy colonies in Bihar, Delhi, Jharkhand, Rajasthan, Uttarakhand, Uttar Pradesh, and West Bengal.

Over the past 24 years, NLRIF has undertaken significant projects to control leprosy and promote disability inclusion. These projects have made substantial contributions to public health and community development.

As part of NLRIF's planning for the next five years, we are conducting an evaluation to assess the impact and effectiveness of its various projects and interventions. This evaluation will provide valuable insights and lessons learned, ultimately helping to advocate for the replication of successful initiatives by the government and other stakeholders.

Procedure

During this evaluation, we will ask questions related to the impact of specific projects on target groups, the acceptability of these projects by the government health system and the community, ease of implementation, behaviour change among beneficiaries, community, and government health staff, cost-effectiveness of different models/approaches, future implementation needs and modifications, and key outcomes and success stories.

Your responses will be crucial in helping us understand the effectiveness of these projects and how they have benefited the community.

Voluntary participation

Participation in this evaluation is entirely voluntary. You are not obliged to participate, and you can withdraw your consent at any time during the evaluation without any consequences. You may also choose not to answer questions you are uncomfortable with. Your decision to participate or not will not affect your relationship with NLRIF or the community in any way.

Risks/Benefits

There are minimal risks associated with participating in this evaluation. Your responses will be kept confidential, and no personally identifiable information will be shared. Some questions may be sensitive, but you have the right to refuse to answer any questions without any consequence.

You will not receive any monetary compensation or personal benefits for participating in this evaluation. However, your insights will be valuable for us to improve our projects and interventions, benefiting the community and potentially contributing to broader public health initiatives.

Confidentiality

Your privacy is important to us. Your participation in this evaluation and the information you provide will be kept confidential. Your responses will be de-identified, meaning they will not contain your name or other information that can directly identify you. We will also ask others in the group to keep what was said during the evaluation confidential.

Do you have any questions about the evaluation or concerns you would like to raise before we start?

If you have any questions or concerns about this evaluation, you may contact Mr. Manav Sharma at manav.s@athenainfonomics.com. For any concerns regarding the ethical procedures for this study, you may contact Member Secretary of Sigma IRB at irb.sigma@sigma-india.in/+91 1141063450.

Consent

Consent:	Yes	No
Do you understand the purpose of this study?		
Should we explain the process again?		
Do you have any questions?		
Do you consent to participate in this discussion based on the above information?		
Do you consent for this interview to be recorded?		

Documentation	Yes	No
We have/had this Informed Consent Form read to us.		
We understand the purpose of the research study.		
Our questions and/or concerns have been answered to my satisfaction.		

For the Enumerator: I confirm that I have read the consent form and personally explained the nature and extent of the planned research, procedures, risks and benefits, and confidentiality of personal information.

Enumerator's Name and Signature: ----------

Date of Interview: ----------

Annexure II: Discussion Guide for Community Members

Potentials Respondents: Representatives from Community-Based Organizations (CBOs), PRI members, Peer Groups, and SHGs

Background Information:

1. Can you briefly describe your involvement in the projects/initiatives in your community? (e.g., PRI member, SHG representative, CBO leader)
    a. Probe: How long have you been involved, and in what capacity?

Project Impact:

2. From your perspective, what changes or improvements have you observed in your community since the initiation of the NLRIF projects?
    a. Probe: In terms of healthcare, disability management, community involvement, etc.
3. Can you share any specific examples or stories of individuals, organizations, or families who have benefited from these projects?
    a. Probe: How have their lives changed?
4. How do you think gender plays a role in how individuals affected by leprosy or disabilities experience stigma within your community?
    a. Probe: Are there gender-specific stigmas or stereotypes that you've observed?
5. Have these projects made any efforts to address or reduce the stigma associated with leprosy, disabilities, or gender-related issues within your community?
    a. Probe: Can you share examples of successful stigma reduction efforts?
6. **For PRI Members:** From your perspective, what notable changes or improvements have you noticed in your community since these projects were initiated?
    a. Probe: Particularly in terms of healthcare, disability management, and community engagement.

Community Engagement:

7. How have these projects engaged your community or organization (SHGs, PRIs, CBOs) in their activities?
    a. Probe: Were you involved in project planning, decision-making, or implementation?
8. **For CBO Focal Person:** How has your Community Based Organization been engaged in the activities of these projects?
    a. Probe: Were you involved in project planning, decision-making, or implementation
9. **For Peer Group:** Can you share how peer groups have been actively involved in the project activities?
    a. Probe: Were there any specific roles or responsibilities assigned to peer groups?

(For Self-Care at Colonies)

7a. How has the SCC at Colonies initiative specifically impacted your community and its members in terms of disability care and self-care practices?

(For Self-Care at PHCs)

7b. How has the SCC at PHCs initiative specifically impacted your community and its members in terms of disability care and self-care practices?

(For Combined SCCs)

7c. How has the Combined SCCs initiative specifically impacted your community and its members in terms of disability care and self-care practices?

(For Homebased Selfcare)

4d. How has the Homebased Selfcare initiative facilitated disability care practices in your community, especially among those affected by leprosy?

(For Disability Inclusive Development)

4e. How has the Disability Inclusive Development project empowered community organizations like yours in promoting disability care and inclusion (particularly availing government schemes/services)?

Project Challenges:

10. Have you encountered any challenges or obstacles related to the implementation of these projects in your community?
    a. Probe: Can you describe these challenges and their impact?

Support and Collaboration:

11. How has the collaboration between community members and project staff been in terms of supporting persons affected by leprosy or disabilities?
    a. Probe: Were there any difficulties or successes in this collaboration?

Awareness and Education:

12. Have these projects contributed to raising awareness about leprosy, disabilities, and self-care practices in your community?
    a. Probe: What specific activities or methods were effective in raising awareness?
13. **For Peer Group:** From your perspective as a peer group member, have these projects contributed to raising awareness about leprosy, disabilities, and self-care practices within your community?

Project Sustainability:

14. In your opinion, how can these projects be sustained and continued to benefit your community in the long term?
    a. Probe: What efforts have you taken for receiving the government schemes; and for your long-term development?
    b. What support or resources are needed to ensure project sustainability?

Feedback and Recommendations:

15. Do you have any suggestions or recommendations for improving the projects or addressing specific issues?
    a. Probe: What can be done differently to enhance the impact of these initiatives?

Conclusion and Closing:

- I want to express my heartfelt thanks for your time and expertise. Your input will significantly impact the future of these initiatives.

- If you have any further thoughts or suggestions, please don't hesitate to reach out. Your ongoing engagement is essential.
- Once again, thank you for your dedication to improving leprosy and disability care programs.

Annexure III: Discussion Guide for Block and District Level Functionaries

Potential Respondents: DLOs, VBD officer, MOs, Facilitators, and other government staff involved in project implementation

Background Information:

1. Can you briefly describe your role and responsibilities within the healthcare system and your involvement with the leprosy and disability care projects/initiatives in your area by NLR?
    a. Probe: How long have you been in this role, and what is your experience with these projects?
2. **For DLO/ VBDO:** Can you provide an overview of your role and responsibilities within the healthcare system, particularly in the context of leprosy and disability care?
    a. Probe: How long have you held this position, and what is your prior experience with these projects?
3. **For DLO/ VBDO:** Could you elaborate on the role of your district health office in the implementation of the leprosy projects and their impact on disability care in these communities?

Project Impact and Outcomes:

4. From your perspective, what have been the key outcomes or impacts of these projects (by NLR) on disability care, leprosy (and filaria as applicable) management, and community health in your district/block?
    a. Probe: Can you provide specific examples or success stories related to these projects?

Community Engagement and Collaboration:

5. How have these projects engaged local communities, PRIs, and healthcare facilities at the district/block level?
    a. Probe: Were there any collaborative efforts between different stakeholders?

(For Self-Care at Colonies)

5a. Can you elaborate on the role of your district/block health office in the implementation of the Selfcare Campat Colonies and its impact on disability care in these communities?

(For Self-Care at PHCs)

5b. How has your district/block health office collaborated with the SCC at PHCs initiative to enhance disability care practices within your jurisdiction?

(For Combined SCCs)

5c. In what ways has your district/block health office supported the Combined SCCs project in promoting self-care practices and disability management among local communities?

(For Homebased Selfcare)

5d. Describe the involvement of your district/block health office in the Homebased Selfcare initiative, and how it has contributed to disability care at the grassroots level.

(For Disability Inclusive Development)

5e. How has your district/block health office worked in tandem with the Disability Inclusive Development project to promote disability care and inclusion within your region?

Challenges and Solutions:

6. Have there been any challenges or obstacles encountered during the implementation of these projects at the district/block level?
    a. Probe: Can you provide examples of how these challenges were addressed or mitigated?

Training and Capacity Building:

7. How has your office supported the training and capacity building of healthcare staff (ASHAs, ANMs) and community workers involved in these projects?
    a. Probe: What training methods or strategies have proven effective?

Sustainability and Future Plans:

8. In your view, what measures can be taken to ensure the sustainability of these projects in your district/block? What measures have already been taken? By whom?
    a. Probe: Are there any plans for scaling up or expanding these initiatives in the future?

Monitoring and Reporting:

9. Can you describe the monitoring and reporting mechanisms in place to track the progress of these projects within your district/block?
    a. Probe: How frequently are project activities monitored, and what data is collected?

Feedback and Recommendations:

10. Do you have any specific recommendations or suggestions for enhancing the effectiveness of these projects or addressing any ongoing issues?
    a. Probe: Are there any areas where additional support or resources are needed?

Conclusion and Closing:

- I want to express my heartfelt thanks for your time and expertise. Your input will significantly impact the future of these initiatives.
- If you have any further thoughts or suggestions, please don't hesitate to reach out. Your ongoing engagement is essential.
- Once again, thank you for your dedication to improving leprosy and disability care programs.

Annexure IV: Discussion Guide for NLRIF Staff and Consultants

Potential Respondents: NLRIF staff, Partner Organizations and Consultants

Background Information:

1. Please provide an overview of your role within the NLR India Foundation (NLRIF) or as a consultant and your involvement in the leprosy and disability care projects.
    a. Probe: How long have you been associated with NLRIF, and what is your specific role in these projects?

Project Goals and Objectives:

2. Can you articulate the primary goals and objectives of the projects you have been involved in?
    a. Probe: How have these goals evolved over time, and what were the initial intentions of the projects?

Project Implementation:

3. Describe the key activities and strategies that have been employed to implement these projects successfully.
4. Were there any innovative or unique approaches used in project implementation?

Collaboration and Partnerships:

5. How has NLRIF collaborated with other stakeholders, including government bodies, healthcare institutions, and local communities, to achieve project goals?
    a. Probe: Can you share any experiences or challenges related to collaboration?

Impact and Outcomes:

6. From your perspective, what have been the most significant impacts or outcomes of these projects on disability care, leprosy and lymphatic Filariasis management, and community health?
    a. Probe: Can you provide specific examples or success stories that highlight these impacts?

Challenges Faced:

7. Have there been any notable challenges or obstacles encountered during project implementation, and how were they addressed?
    a. Probe: Were there any lessons learned from these challenges that influenced project adaptations?

Monitoring and Evaluation:

8. How have you monitored and evaluated the progress and effectiveness of these projects?
    a. Probe: What data and metrics have been used to measure project success?

Capacity Building and Training:

9. Describe the efforts made to build the capacity of project staff, including healthcare workers, community volunteers, and beneficiaries.
    a. Probe: Were there any specific training methodologies or approaches that proved particularly effective?

Sustainability and Future Plans:

10. In your view, what measures can be taken to ensure the sustainability of these projects in the long term? What sustainability measures have already been taken? Any evidence or indicator of sustainability?
    a. Probe: Are there any plans or strategies for scaling up or expanding these initiatives?

Community Engagement and Empowerment:

11. How have these projects engaged and empowered local communities, Self-Help Groups (SHGs), and other community-based organizations?
    a. Probe: Can you provide examples of community-led initiatives or involvement in project activities?

Feedback and Reflections:

12. What feedback or reflections do you have regarding the overall impact and journey of these projects?
    a. Probe: Are there any aspects of the projects that you believe require further attention or improvement?

Recommendations and Future Directions:

13. Based on your experience, do you have any specific recommendations or suggestions for enhancing the effectiveness of similar projects or addressing emerging challenges?
    a. Probe: Are there any new directions or areas of focus that you believe should be considered for future projects?

Conclusion and Closing:

- I want to express my heartfelt thanks for your time and expertise. Your input will significantly impact the future of these initiatives.
- If you have any further thoughts or suggestions, please don't hesitate to reach out. Your ongoing engagement is essential.
- Once again, thank you for your dedication to improving leprosy and disability care programs.

Annexure V: Discussion Guide for Program Managers and Trainers

Potential Respondents: Program managers and trainers

Background Information:

1. Please provide an overview of your role as a Program Manager or Trainer and your involvement in the leprosy and disability care projects.
    a. Probe: How long have you been associated with these projects, and what specific responsibilities do you hold?

Project Goals and Objectives:

2. Can you articulate the primary goals and objectives of the projects you oversee or train staff for?
    a. Probe: How have these goals evolved over time, and what were the initial intentions of the projects?

Training and Capacity Building:

3. Describe the training and capacity-building initiatives you have led or been a part of within these projects.
    a. Probe: Were there any innovative or unique approaches used in training project staff or beneficiaries?

Implementation Oversight:

4. How do you oversee and support the implementation of project activities on the ground?
    a. Probe: Can you share examples of your involvement in project monitoring and supervision?

Challenges and Adaptations:

5. Have there been any notable challenges or obstacles encountered during project implementation, and how were they addressed?
    a. Probe: Were there any lessons learned from these challenges that influenced project adaptations?

Impact and Outcomes:

6. From your perspective, what have been the most significant impacts or outcomes of these projects on disability care, leprosy management, and community health?
    a. Probe: Can you provide specific examples or success stories that highlight these impacts?

Collaboration and Partnerships:

7. How have you facilitated collaboration with other stakeholders, including government bodies, healthcare institutions, and local communities, to achieve project goals?
    a. Probe: Can you share any experiences or challenges related to collaboration?

Monitoring and Evaluation:

8. How do you ensure the progress and effectiveness of these projects are monitored and evaluated effectively?

a. Probe: What data and metrics have been used to measure project success, and how do you use this data for decision-making?

Community Engagement and Empowerment:

9. How have these projects engaged and empowered local communities, Self-Help Groups (SHGs), and other community-based organizations?
    a. Probe: Can you provide examples of community-led initiatives or involvement in project activities?

Sustainability and Future Plans:

10. In your view, what measures can be taken to ensure the sustainability of these projects in the long term?
    a. Probe: Are there any plans or strategies for scaling up or expanding these initiatives?

Feedback and Reflections:

11. What feedback or reflections do you have regarding the overall impact and journey of these projects from a program management and training perspective?
    a. Probe: Are there any aspects of the projects that you believe require further attention or improvement?

Recommendations and Future Directions:

12. Based on your experience, do you have any specific recommendations or suggestions for enhancing the effectiveness of similar projects or addressing emerging challenges?
    a. Probe: Are there any new directions or areas of focus that you believe should be considered for future projects?

Conclusion and Closing:

- I want to express my heartfelt thanks for your time and expertise. Your input will significantly impact the future of these initiatives.
- If you have any further thoughts or suggestions, please don't hesitate to reach out. Your ongoing engagement is essential.
- Once again, thank you for your dedication to improving leprosy and disability care programs.

Annexure VI: Semi-Structured Tool for Frontline Health Workers

Potential Respondents: ASHAs, ANMs, other healthcare workers.

Background Information:

1. Please provide some background on your role as an ASHA/ANM and your involvement in the leprosy and disability care projects.
    a. Probe: How long have you been part of these projects, and what areas do you primarily cover in your work?

Project Awareness and Training:

2. Were you aware of the leprosy and disability care projects when they started?
    a. Probe: Have you received any specific training related to these projects, including self-care methods or disability prevention?
    b. On a scale of 1 to 5, how would you rate the effectiveness of the training you received? (1 = Not Effective, 2 = Somewhat Ineffective, 3 = Neutral, 4 = Somewhat Effective 5 = Highly Effective)

Project Activities and Implementation:

3. Can you describe your role and responsibilities in implementing the project activities within your community or area?
    a. Probe: How do you identify and refer persons affected by leprosy or disabilities to the project services?

Community Engagement and Awareness:

4. How do you engage with the community to raise awareness about leprosy, disabilities, and the project's goals?
    a. Probe: Have you encountered any challenges or successes in community engagement?
    b. On a scale of 1 to 5, how would you rate the level of community awareness about leprosy and disabilities in your area? (1 = Low Awareness, 2 = Limited Awareness, 3 = Moderate Awareness, 4 =High Awareness,5 = Very High Awareness)
5. How were you engaged in the NLRIF leprosy camp support and related activities?

Training and Support to Beneficiaries:

6. Have you provided training or support to persons affected by leprosy or disabilities as part of these projects?
    a. Probe: What types of training or assistance have you offered, and how do you ensure its effectiveness?
    b. Approximately, how many beneficiaries have you provided training or support to in the last month?
7. Have you received Leprosy related training?
    a. If yes, who provided this training?
    b. If yes, what is the frequency of the trainings?
    c. If not, why not?

Challenges and Solutions:

8. Have there been any challenges or obstacles you've faced while working on these projects, and how have you addressed them?
    a. Probe: Are there any innovative approaches or solutions you've used to overcome challenges?

Impact and Outcomes:

9. From your perspective, what impact have these projects had on the lives of persons affected by leprosy or disabilities in your community?
    a. Probe: Can you share specific examples or stories that highlight this impact?
    b. Approximately, how many beneficiaries have shown improvement in their condition since the start of the project?

Community Involvement and Empowerment:

10. How were the community members, including Self-Help Groups (SHGs), were encouraged to actively participate in project activities?
    a. Probe: Who is responsible for conducting these activities?
    b. Probe: Have you seen any positive changes in the community's involvement or empowerment?

Monitoring and Reporting:

11. What processes or tools do you use to monitor and report on the progress and outcomes of the projects?
    a. Probe: How often do you conduct follow-up visits or assessments?
    b. How frequently do you conduct follow-up visits on average? (e.g., Weekly, Monthly, Quarterly)

Feedback and Reflections:

12. What feedback or personal reflections do you have about your experience working on these projects?
    a. Probe: Are there any aspects of the projects that you believe have been particularly effective or need improvement?
    b. On a scale of 1 to 5, how satisfied are you with your involvement in these projects? (1 = Very Dissatisfied, 2 = Somewhat Dissatisfied, 3 = Neutral, 4 = Somewhat Satisfied, 5 = Very Satisfied)

Recommendations and Future Directions:

13. Based on your experience, do you have any recommendations or suggestions for enhancing the effectiveness of similar projects or addressing emerging challenges?
    a. Probe: Are there any specific areas or activities you believe should be prioritized in future projects?
    b. Please rank the top three areas you believe should be prioritized in future projects. (1 = Highest Priority, 2 = Moderate Priority, 3 = Low Priority)

Conclusion:

- I want to express my heartfelt thanks for your time and expertise. Your input will significantly impact the future of these initiatives.
- If you have any further thoughts or suggestions, please don't hesitate to reach out. Your ongoing engagement is essential.
- Once again, thank you for your dedication to improving leprosy and disability care programs.

Annexure VII: Structured Tool for Beneficiaries' Survey

S. No.	Questions	Response	Skips/Remarks
	Background Information		
A1	Surveyor's Name		List
A2	Surveyor's Contact Number		Auto Coded
A3	Date of Interview		Auto Coded
A4	Interview start time	HH:MM	Auto Coded
A5	State	1. Bihar 2. Jharkhand 3. Uttar Pradesh 4. Rajasthan 5. West Bengal	Single Code
A6	District	1. Patna (Bihar) 2. Bhojpur (Bihar) 3. Buxar (Bihar) 4. Aurangabad (Bihar) 5. Bokaro (Jharkhand) 6. Dhanbad (Jharkhand) 7. Koderma (Jharkhand) 8. Hazaribagh (Jharkhand) 9. Bareilly (UP) 10. Moradabad (UP) 11. Shahjahanpur (UP) 12. Kanpur (UP) 13. Kannauj (UP) 14. Sitapur (UP) 15. Pali (Rajasthan) 16. Alwar (Rajasthan) 17. Jaipur (Rajasthan) 18. West Medinipur (WB) 19. Jhargram & Bankura (WB) 20. Hoogly & Howrah (WB)	Single Code, Link to A5
A7	Block		Open Code
A8	Village/Slum/ Ward		Open Code
B1	Do you want to participate in this survey?	1. Yes 2. No	Terminate Survey if B1=2
	Respondent Information		
B2	Name of the respondent		Open End
B3	Gender	◯Male ◯Female ◯Others ◯Prefer not to answer	Single Code
B4	Age (in years)		Open End
B5	Education level	◯Never went to school ◯ Less than class 5 ◯ Completed class 5th ◯ Completed class 8th ◯ Completed class 10th ◯ Completed class 12th	Single Code

S. No.	Questions	Response	Skips/Remarks
		◯ Completed graduation (10+2+3) ◯ Completed Post Graduation ◯ Completed Vocational training ◯ Diploma 1 year or higher ◯ Other (please specify)	
B6	Are you the head of the household?	◯Yes ◯No	Single Code
B7	If No, what is the gender of the Household Head?	◯Male ◯Female ◯Others ◯Prefer not to answer	Single Code, Applicable if B7=2
B8	If the response to the above question is 'no', what is your relationship with the head of the household?	◯Spouse ◯Father ◯Mother ◯Mother-in-Law ◯Father-in-Law ◯Elder Sibling ◯Others (Specify)	Single Code, Applicable if B7=2
B9	How long have you been receiving services from the leprosy and disability care projects	◯Years: ◯Months:	Open Code
B10	Which of the following NLRIF services did you received?	☐ Vikalp ☐ Combined Self-Care (CSC) Camps ☐ Disability Inclusive Development (DID) ☐ Home-based Self-Care in West Bengal ☐ Self-care at PHC ☐ Selfcare in the Colony ☐ Urban Leprosy Programme	Multi Code
Respondent Experience			
C1	How did you become aware of the leprosy and disability care projects	☐ Through a community event or meeting ☐ Through a health worker (ASHA/ANM) ☐ Through a friend or family member ☐ Other (please specify)	Multi Code
C2	Prior to participating in the projects, how knowledgeable were you about leprosy and disability care?	◯Not knowledgeable at all ◯Somewhat knowledgeable ◯No Change ◯Knowledgeable ◯Very knowledgeable	Single Code
C3	Which project services have you received?	☐ Self-care training ☐ Disability assessment ☐ Distribution of assistive devices ☐ Reconstructive surgery support ☐ Psychological support ☐ Other (please specify)	Muti Code

S. No.	Questions	Response	Skips/Remarks
C4	How satisfied are you with each of the project services you have received? (Rate each service from 1 to 5, where 1 = Very Dissatisfied, 5 = Very Satisfied)	a. Self-care training: b. Disability assessment: c. Distribution of assistive devices: d. Reconstructive surgery support: e. Psychological support:	Single, Options Selected in C3 to be visible
C5	Have you personally experienced/observed a reduction in social stigma since being associated with the NLRIF projects?	1. Yes 2. Maybe 3. No	Single Code
Self-Care and Knowledge Improvement			
D1	Has the project helped you improve your knowledge about leprosy?	◯Yes, significantly ◯Yes, to some extent ◯No, not really	Single Code
D2	Has the project helped you improve your knowledge about selfcare?	◯Yes, significantly ◯Yes, to some extent ◯No, not really	Single Code
D3	Has the project helped you improve your knowledge about disease prevention?	◯Yes, significantly ◯Yes, to some extent ◯No, not really	Single Code
D4	Are you regularly practicing self-care methods learned through the project?	◯Yes, regularly ◯Occasionally ◯No, not at all	Single Code
D5	Do you feel that your participation in the project has positively impacted your community's awareness of leprosy and /disabilities?	◯Yes, significantly ◯Yes, to some extent ◯No, not really	Single Code
D6	How would you rate the overall impact of the projects on your life and well-being?	◯Very Positive ◯Positive ◯Neutral ◯Negative ◯Very Negative	Single Code
D7	If you have received assistive devices (e.g., crutches, protective footwear), how frequently do you use them?	◯Daily ◯Weekly ◯Occasionally ◯Rarely ◯Never	Single Code
D8	Have the assistive devices improved your mobility and quality of life?	◯Yes, significantly ◯Yes, to some extent ◯No, not really	Single Code, Applicable if D5=1
Impact Overview			
E1	How has your participation in community activities or social events changed since your involvement in the project?	1. Not at all 2. Slightly 3. Moderately 4. Considerably 5. Significantly	Single Code
E2	How many community or social events have you actively participated in over the past year compared to before the project's implementation?		Open Code
E4	What was your average monthly income before the project's intervention?	◯Less than 10000 ◯10000-15000 ◯15001 –30,000 ◯30,000+ ◯Do Not Know	

S. No.	Questions	Response	Skips/Remarks
E5	What is your average monthly income now, after participating in the project?	◯Less than 10000 ◯10000-15000 ◯15001 –30,000 ◯30,000+ ◯Do Not Know	
E6	Have you been able to start or expand a business or income-generating activity as a result of the project?	◯Yes ◯No	Single Code
E7	How has the project influenced your children's attendance and performance in school?	◯Improved ◯No Change ◯Declined	Single Code
E8	On average, how many additional hours per week are your children spending on educational activities (e.g., studying, homework) since the project's involvement?		Open Code
E9	Have you noticed an increase in the number of educational resources (e.g., books, tutoring) available to your children as a result of the project?	◯Yes ◯No	Single Code
E10	How much do you spend on travelling to leprosy camps/project sites/Doctor per visit?	◯Not Applicable ◯Less than 50 ◯50-100 ◯100-200 ◯200-500 ◯500-1000 ◯Over 1000	Single Code
E11	How many trips do you take per week?	◯ Not Applicable ◯Less than 2 ◯2-3 ◯3-5 ◯Over 5	Single Code
E12	What is the consultation fees for the Doctors?	◯No Fees ◯50-100 ◯100-200 ◯200-500 ◯500-1000 ◯Over 1000	Single Code
E13	How much do you spend on Assistive Devices, Dressing Materials, medicines etc per week.	◯No Fees ◯Less than 100 ◯100-500 ◯500-1000 ◯1000-2000 ◯More than 2000	Single Code
E14	Do you miss work due to attending camps/doctor visits/disease symptoms	◯Yes ◯No	Single Code
E17	How many days in a week do you miss work/income generating activity due to attending camps/doctor visits/disease symptoms	◯No Days ◯1-2 ◯2-3 ◯3-4 ◯Over 4 Days	Single Code
E16	How much wages are lost per day due to missing work?	◯No Wages ◯100-500 ◯500-1000 ◯1000-2000 ◯2000-5000 ◯5000-10000	Single Code, Applicable if E14=1

S. No.	Questions	Response	Skips/Remarks
		◯Over 10000	
	Life Skills Education (LSE)		
F1	On a scale from 1 to 5, how confident do you feel in your ability to make informed decisions about your health and well-being?	◯Not confident at all ◯Slightly Confident ◯Moderately Confident ◯Quite Confident ◯Very confident	Single Code
F2	On a scale from 1 to 5, How often do you use life skills and practice it in managing your daily activities and challenges?	◯Rarely ◯Occasionally ◯Sometimes ◯Frequently ◯Always	Single Code
F3	Have you noticed any improvement in your problem-solving skills after participating in life skills education sessions?	◯No Improvement ◯Slight Improvement ◯Moderate Improvement ◯Considerable Improvement ◯Significant Improvement	Single Code
F4	How has Life skills education helped you to manage your day to day activities or the work that you do in your life?		Open End
F5	On a scale from 1 to 5, how effective do you find the life skills education sessions in enhancing your overall quality of life?	◯Not Effective at All ◯Slightly Effective ◯Moderately Effective ◯Very Effective ◯Extremely Effective	Single Code
F6	On what event do you felt that you have applied life skills and overcome the challenges, site few examples?		Open End
	Sexual & Reproductive Health Education (SRH)		
G1	Have the SRH education sessions increased your awareness about safe sexual practices and Responsible Sexual Behaviour?	◯Yes ◯No	Single Code
G2	On a scale from 1 to 5, how comfortable are you discussing sexual and reproductive health issues and family planning with healthcare providers?	◯Very Uncomfortable ◯Uncomfortable ◯Neutral ◯Comfortable ◯Very Comfortable	Single Code
G3	On a scale from 1 to 5, how comfortable are you discussing sexual and reproductive health issues and family planning with teachers?	◯Very Uncomfortable ◯Uncomfortable ◯Neutral ◯Comfortable ◯Very Comfortable	Single Code
G4	On a scale from 1 to 5, how comfortable are you discussing sexual and reproductive health issues and family planning with family members (sisters, etc)?	◯Very Uncomfortable ◯Uncomfortable ◯Neutral ◯Comfortable ◯Very Comfortable	Single Code
G5	How often do you practice safe sexual behaviours after attending SRH education sessions?	◯Rarely ◯Occasionally ◯Sometimes ◯Frequently ◯Always	Single Code
G6	Have you accessed reproductive health services (such as family planning consultations, use of contraceptive /condoms, safe abortion, STI screenings)	◯Yes ◯No	Single Code

S. No.	Questions	Response	Skips/Remarks
	after participating in SRH education sessions?		
G7	How has SRH education impacted your overall well-being and relationships?		Open End
	Social Participation		
H1	On a scale from 1 to 5, how has the project improved your sense of belonging and acceptance within your community?	◯Not at All ◯Slightly ◯Moderately ◯Considerably ◯Significantly	Single Code
H2	How often do you engage in community activities or events since participating in the project?	◯Rarely ◯Occasionally ◯Sometimes ◯Frequently ◯Always	Single Code
H3	Have you noticed an increase in social support from your community after the implementation of the project?	◯Yes ◯No	Single Code
H4	On a scale from 1 to 5, how confident are you in participating in community discussions and decision-making processes?	◯Not Confident at All ◯Not Very Confident ◯Neutral ◯Confident ◯Very Confident	Single Code
H5	Have you been involved in any community development initiatives or projects as a result of the skills and knowledge gained through this project?	◯Yes ◯No	Single Code
	Income Generation		
I1	Has the project helped you in generating additional income or improving your livelihood?	◯Yes ◯No	Single Code
I2	On a scale from 1 to 5, how has the project contributed to enhancing your vocational skills and employability?	◯Not at All ◯Slightly ◯Moderately ◯Considerably ◯Significantly	
I3	Have you started or expanded a small business as a result of the project's support?	◯Yes ◯No	
I4	How has the project influenced your ability to save and manage finances?		Open Ended
I5	On a scale from 1 to 5, how satisfied are you with the financial support and training provided by the project for income generation activities?	◯Not Satisfied at All ◯Not Very Satisfied ◯Neutral ◯Satisfied ◯Very Satisfied	Single Code
	Education of Children		
J1	Have your children's access to education improved due to the project's interventions?	◯Yes ◯No	Single Code
J2	On a scale from 1 to 5, how has the project contributed to enhancing the quality of education received by your children?	◯Not at All ◯Slightly ◯Moderately ◯Considerably ◯Significantly	Single Code
J3	Have there been improvements in your children's school attendance and	◯Yes ◯No	Single Code

S. No.	Questions	Response	Skips/Remarks
	participation in extracurricular activities after the project's implementation?		
J4	Has the project provided any educational support or scholarships for your children?	◯Yes ◯No	Single Code
J5	On a scale from 1 to 5, how confident are you in supporting your children's education due to the assistance received from the project?	◯Not Confident at All ◯Not Very Confident ◯Neutral ◯Confident ◯Very Confident	Single Code
Project Specific Insights – VIKALP, Applicable if B10=1			
K1	Have you received calls or information from the call center regarding your leprosy treatment and follow-up?	◯Yes ◯No	Single Code
K2	How satisfied are you with the information and support provided by the call center regarding leprosy and your treatment?	◯Very Satisfied ◯ Satisfied ◯Neutral ◯Dissatisfied ◯Very Dissatisfied	Single Code
K3	Did you collaborate with the district leprosy staff (DLS) for your case management and follow-up?	◯Yes ◯No ◯Not Sure	Single Code
K4	How helpful was the collaboration between the call center and district leprosy staff in managing your leprosy treatment?	◯Very Helpful ◯Helpful ◯Neutral ◯Not Helpful ◯Not Applicable	Single Code
K5	Did you receive follow-up calls from the call centre regarding your self-care practices?	◯Yes ◯No	Single Code
K6	Please select from the following services that you have been able to receive information from the project?	1. Improve drug adherence to Multi Drug Therapy (MDT) for leprosy. 2. Promote self-care practices 3. Promote preventive chemotherapy 4. – Offer effective counselling on leprosy-related issues.	Multi Code
Project Specific Insights - Combined Self-Care (CSC) Camps, Applicable if B10=2			
L1	Have you attended any of the CSC Camps for self-care training?	◯Yes ◯No	Single Code
L2	How satisfied were you with the training provided at the CSC Camp?	◯Very Satisfied ◯Satisfied ◯Neutral ◯Dissatisfied ◯Very Dissatisfied	Single Code
L3	Did you receive assistive devices at the CSC Camp?	◯Yes ◯No	Single Code
L4	Have you utilized the psychological support provided at the CSC Camps?	◯Yes ◯No	Single Code

S. No.	Questions	Response	Skips/Remarks
L5	Please select from the following services that you have been able to receive information from the project?	- Practice self-care. - Nerve function assessment and disability prevention at PHC - Support for reconstructive surgeries for leprosy and LF. - Training for psychological support for Neglected Tropical Diseases (NTDs). - Disability assessment and information recorded. - Assisting devices provided - Complicated cases referred. - Mental health support using Basic Psychological Support (BPS-N) - Assistive devices distributed.	Multi Code
Project Specific Insights - Disability Inclusive Development (DID) , Applicable if B10=3			
M1	Are you a member of any self-help groups or Organizations of Persons with Disabilities (OPDs) facilitated by the DID project?	◯Yes ◯No	Single Code
M2	How has your involvement in community-based institutions empowered you?	◯Yes, significantly ◯Yes, to some extent ◯No, not really	Single Code
M3	Please select the list of schemes you have been able to access as a beneficiary through the DID project?	1. Adhar card 2. Ration card 3. Disability Certificate 4. UDID (Swablamban) 5. Disability pension 6. MNREGA Job Card 7. Rail Pass 8. Bus Pass 9. Toilet Services 10. Pradhan Mantri Awas Yojna 11. Assistive Devices 12. Bank Loan 13. Social Security (e.g. old age, widowhood) 14. PWD Act (2016) 15. Any Education scheme/service 16. Any Health scheme/service 17. Any Livelihood scheme/service 18. Disability Friendly Voter Booths	Single Code

S. No.	Questions	Response	Skips/Remarks
		19. Assistance at government offices 20. Assistance at Panchayati Raj	
M4	Are you happy with the timeliness of these support/services?	◯Yes ◯No	Single Code
M5	Are you happy with the quality of these support/services?	◯Yes ◯No	Single Code
Project Specific Insights - Home-based Self-Care, Applicable if B10=4			
N1	Are you receiving home-based self-care support from Accredited Social Health Activist (ASHA) workers?	◯Yes ◯No	Single Code
N2	How satisfied are you with the home-based self-care support provided by ASHA workers?	◯Very Satisfied ◯Satisfied ◯Neutral ◯Dissatisfied ◯Very Dissatisfied	Single Code
N3	Have you received assistive and protective devices at your home as part of the home-based self-care project?	◯Yes ◯No	Single Code
N4	Please select the list of schemes you have been able to access as a beneficiary	- Manage disabilities through self-care at their home. - Training for Selfcare - Distribution of assistive and preventive devices - Facilitation of reconstructive surgeries - Continuous monitoring, supervision, and advocacy for Selfcare - Reorientation and Training	Multi Code
Project Specific Insights - Selfcare at PHC, Applicable if B10=5			
O1	Have you attended any self-care training camp/programme/workshops at Primary Health Centers (PHCs) or Community Health Centers (CHCs)?	◯Yes ◯No	Single Code
O2	How has the training at PHCs helped you in managing your leprosy-related disabilities?	◯Yes, significantly ◯Yes, to some extent ◯No, not really	Single Code
O3	Are you practicing self-care regularly as per what you learned at the PHC training?	◯Yes ◯Occasionally ◯No	Single Code
O4	Please select the list of schemes/services you have been able to access as a beneficiary of the project	- Manage Disability through Selfcare - GHC/ANM/ASHA at PHC identify and provide early assessment. - Training on Selfcare Methods - Distributing assistive and protective devices - Reconstruction Surgeries	

S. No.	Questions	Response	Skips/Remarks
		- Motivation from ASHA/ANM/GNM - Peer Support - Reorientation and Training - Mental health support using Basic Psychological Support (BPS-N)	
Project Specific Insights – Selfcare at Colonies, Applicable if B10=6			
P1	Have you attended any self-care training camp/programme/workshops at Colonies	◯Yes ◯No	Single Code
P2	How has the training at leprosy colonies helped you in managing your leprosy-related disabilities?	◯Yes, significantly ◯Yes, to some extent ◯No, not really	Single Code
P3	Are you practicing self-care regularly as per what you learned in training?	◯Yes ◯Occasionally ◯No	Single Code
P4	Please select the list of schemes/services you have been able to access as a beneficiary of the project	- Manage Disability through Selfcare - GHC/ANM/ASHA at PHC identify and provide early assessment. - Training on Selfcare Methods - Distributing assistive and protective devices - Reconstruction Surgeries - Motivation from ASHA/ANM/GNM - Peer Support - Reorientation and Training - Mental health support using Basic Psychological Support (BPS-N)	Multi Code
Project Specific Insights - Urban Leprosy Programme, Applicable if B10=7			
Q1	Have you been referred by frontline health workers to Urban Primary Health Centres (UPHCs) for leprosy services	◯Yes ◯No	Single Code
Q2	How satisfied are you with the leprosy services provided at UPHCs under this program?	◯Very Satisfied ◯Satisfied ◯Neutral ◯Dissatisfied ◯Very Dissatisfied	Single Code
Q3	Has your family and other contacts received Single Dose Rifampicin for Post-Exposure Prophylaxis (SDR-PEP) through this program?	◯Yes ◯No	Single Code
Q4	Please select the list of schemes/services you have been able to access as a beneficiary of the project	- Training on Selfcare - UPH offering leprosy related services - Single Dose Rifampicin	Multi Code

S. No.	Questions	Response	Skips/Remarks
		- Diagnosis and Treatment by MOs at UPHC - Follow up by Frontline Workers - Referred cases to Medical College/District Hospital	

S. No.	Thematic Area	Activity	Unable	Partially Able	Able	Skips
ADL Assessment						
R1	Personal Hygiene	Bathing or showering	0	1	2	Single Code
		Grooming	0	1	2	
		Brushing teeth	0	1	2	
R2	Dressing	Selecting clothing	0	1	2	
		Putting on clothing	0	1	2	
R3	Feeding	Using utensils to eat	0	1	2	
		Preparing simple meals	0	1	2	
R4	Mobility	Walking	0	1	2	
		Transferring	0	1	2	
R5	Toileting	Using the toilet	0	1	2	
		Managing personal hygiene	0	1	2	
R6	Continence	Bowel control	0	1	2	
		Bladder control	0	1	2	
IADL Assessment						
S. No.	**Thematic Area**	**Activity**	**Unable**	**Partially Able**	**Able**	**Skips**
S1	Cooking	Planning meals and grocery shopping	0	1	2	Single Code
		Cooking food safely	0	1	2	
S2	Cleaning and Housekeeping	House cleaning	0	1	2	
		Laundry	0	1	2	
S3	Managing Finances	Paying bills	0	1	2	
		Budgeting	0	1	2	
S4	Medication Management	Organizing and taking medications	0	1	2	
S5	Using Transportation	Driving	0	1	2	
		Using public transportation	0	1	2	
S6	Managing Communication	Using the telephone	0	1	2	
		Using a computer or other communication devices	0	1	2	
Suggestions and Feeback						

T1	Do you have any suggestions or feedback for improving the projects or additional services you would like to see in the future? Please explain.		Open Code
T2	How likely are you to recommend these projects to others in your community?	◯Very Likely ◯Likely ◯Neutral ◯Unlikely ◯Very Unlikely	Single Code
Thank you for time			
A9	Interview End Time	HH:MM	Auto Coded

Annexure VIII: Discussion Guide for Focus Groups with Beneficiaries

Potential Respondents: Project Beneficiaries

Participant Introduction:

1. Ask participants to introduce themselves by sharing their name and a brief background. You can also ask them to mention their gender.

Project Awareness:

2. **Awareness and Knowledge:** How did you first learn about the leprosy projects/initiatives.
    a. (Probe: Was gender a factor in how you became aware of these projects?)
3. What are the most significant self-care practices that you learned during the CSC camps?
    a. Probe: How have they benefited you?

Project Impact:

4. **Personal Impact:** In your experience, how have these projects positively or negatively affected your life and the lives of your family members?
    a. (Probe: Have you noticed any gender-specific impacts, either positive or negative?)
5. **Health and Well-being:** How have these projects influenced your overall health and well-being?
    a. (Probe: Are there gender-related differences in health outcomes that you've observed?)
6. Could you describe an instance where self-care practices taught in the camps prevented or managed a disability effectively?
7. How did the involvement of PRIs and CBOs enhance the effectiveness of the CSC camps in your community?
8. What specific vocational training and skill development opportunities have been most beneficial for persons with disabilities in your community?

Community Engagement:

9. **Community Involvement:** How have you and your community members been engaged in the projects?
    a. (Probe: Were there any gender-related differences in community involvement?)
10. What strategies do you think would be effective in encouraging more persons affected by leprosy and LF to participate in these camps?
11. In your view, what role should the media play in raising awareness about the Rights of Persons with Disabilities (RPWD) Act, 2016?

Challenges and Barriers:

12. **Challenges Faced:** Have you encountered any challenges or obstacles related to accessing project benefits or participating in project activities?
    a. (Probe: Were these challenges gender-specific?)

Support and Empowerment:

13. **Support Received:** What types of support have you received from these projects and the implementing organizations?

a. (Probe: Did you perceive any gender-specific support or empowerment opportunities?)

Awareness and Education:

14. **Raising Awareness:** Have these projects contributed to raising awareness about leprosy, disabilities, and self-care practices in your community?
    a. (Probe: Were gender-specific awareness activities conducted?)

Sustainability and Future Plans:

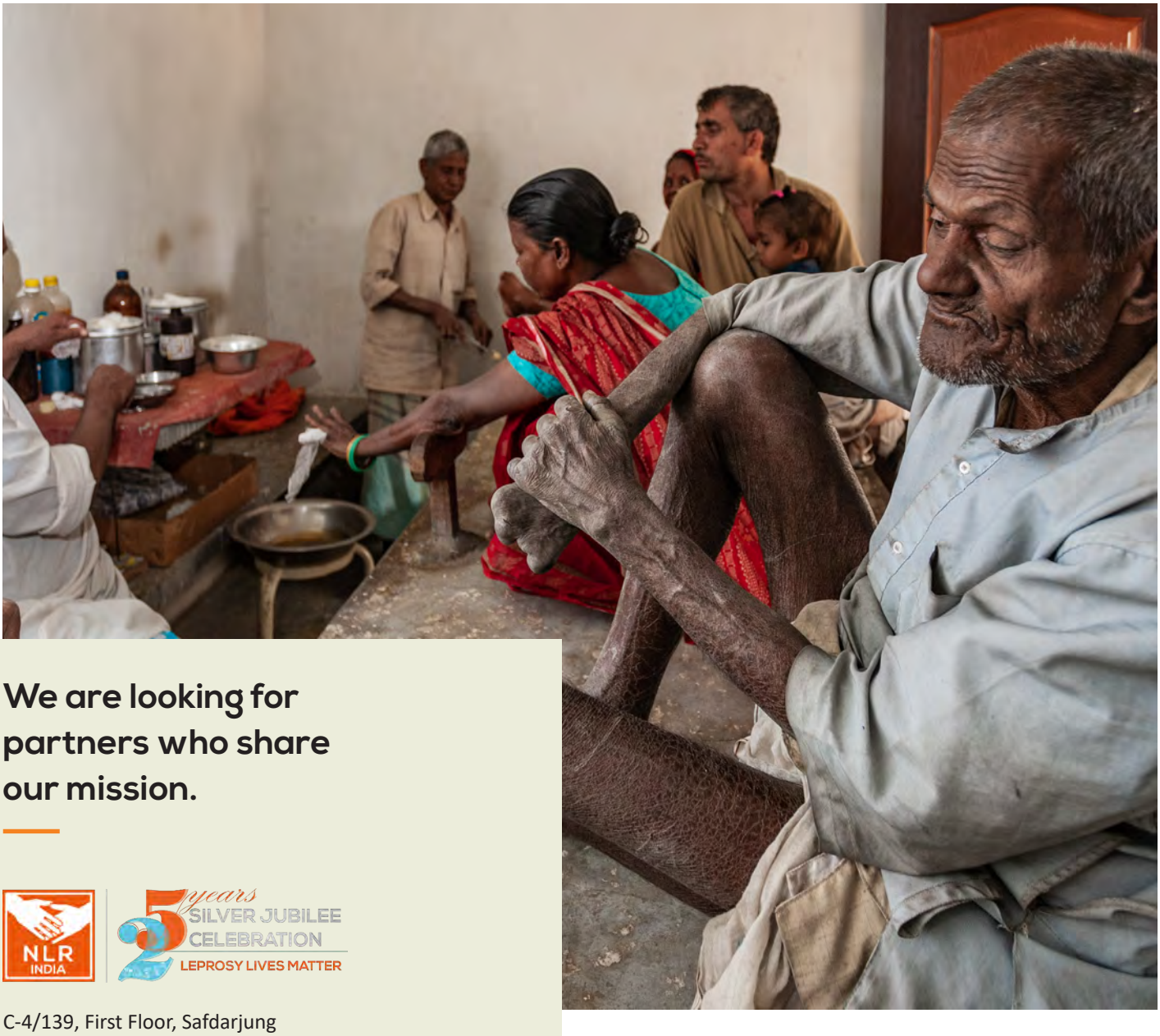
15. **Project Sustainability:** In your opinion, how can these projects be sustained and continued to benefit your community in the long term?
    a. (**Probe:** Are there specific gender-related aspects that should be considered for project sustainability?)

Feedback and Recommendations:

16. **Suggestions for Improvement:** Do you have any suggestions or recommendations for improving the projects or addressing specific issues? (Probe: Are there gender-related considerations that should be addressed in project improvements?)

Conclusion and Closing:

- I want to express my heartfelt thanks for your time and expertise. Your input will significantly impact the future of these initiatives.
- If you have any further thoughts or suggestions, please don't hesitate to reach out. Your ongoing engagement is essential.
- Once again, thank you for your dedication to improving leprosy and disability care programs.



We are looking for partners who share our mission.

NLR INDIA

25 years SILVER JUBILEE CELEBRATION
LEPROSY LIVES MATTER

C-4/139, First Floor, Safdarjung
Development Area, New Delhi, 110016
Phone Number: +91-11-26611215/16
info@nlrindia.org
www.nlrindia.org