NCPEDP

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Baseline Report

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Ensuring Social Security for Individuals Affected by Leprosy

Contents

1 Acknowledgements

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[1] National Centre for Promotion of Employment for Disabled People (NCPEDP), for their consistent support throughout my study. Their guidance and assistance have been invaluable in navigating the complexities of this research.

[2] The Leprosy Mission India (TLM), for its pivotal role in this study. Many thanks to their team, especially those at the Barabanki, Ayodhya, and Prayag centres, where I collected a significant portion of the responses. The support and guidance provided by the staff were crucial in sensitising processes and facilitating data collection.

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[3] APAL India, for their assistance in formulating recommendations during group discussions. Their contributions, alongside the participation of TLM India, enriched the quality of the insights gathered.

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[1] More about NCPEDP

[2] More about TLM India

[3] More about APAL India

2 Executive Summary

[4] Leprosy, a chronic infectious disease caused by Mycobacterium Leprae, has persisted throughout human history, with mentions found in ancient texts. It primarily affects the skin and peripheral nerves and, if left untreated, can lead to progressive and permanent disabilities. Despite being curable with multidrug therapy (MDT), leprosy remains a significant global health concern, particularly in regions with poor access to healthcare.

Scope of the Problem

Leprosy, categorised as a neglected tropical disease (NTD), continues to affect over 120 countries worldwide, with over 200,000 new cases reported annually. While global efforts have led to the elimination of leprosy as a public health problem in many countries, it remains prevalent in several regions, notably in South-East Asia. Stigma and discrimination against individuals affected by leprosy exacerbate the challenges they face, compounding the disease's impact.

Transmission

Transmission of leprosy occurs primarily through droplets from the nose and mouth during prolonged, close contact with untreated cases. However, the disease is not easily spread through casual contact and ceases transmission once treatment begins. This underscores the importance of early diagnosis and intervention to prevent further transmission and mitigate the disease's effects.

Diagnosis

Diagnosing leprosy relies primarily on clinical assessment, though laboratory-based services may be necessary for complex cases. Key diagnostic criteria include the presence of specific skin lesions, peripheral nerve involvement, and microscopic detection of bacilli in slit-skin smears. Classification into paucibacillary (PB) and multibacillary (MB) cases guides treatment strategies.

Treatment

MDT - comprising dapsone, rifampicin, and clofazimine - is the recommended treatment regimen for leprosy. While effective, early diagnosis and prompt initiation of treatment are crucial to preventing disabilities associated with the disease. The World Health Organisation (WHO) provides MDT free of cost to endemic countries, facilitating access to treatment for affected individuals.

Prevention

Beyond case detection and treatment, WHO recommends proactive measures to prevent leprosy transmission. This includes tracing and administering preventive chemotherapy to the

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[4] Source of Executive Summary

household and social contacts of affected individuals, complementing efforts to interrupt transmission and reduce disease burden.

3 Background

With a population exceeding 220 million, Uttar Pradesh (UP) is India's most populous state. Census 2011 data reveals that the state's population growth rate was 20.23% over the previous decade, marking a significant increase. However, the sex ratio of 912 females per 1000 males remains below the national average, and literacy rates are improving but still modest, with 67.68% overall literacy, with a notable gender gap where male literacy stands at 77.28% and female literacy at 57.18%.

The state's religious demographics show Hinduism as the dominant faith, followed by Islam, with Christianity, Jainism, Sikhism, and Buddhism also represented. The urban population of UP constitutes 22.27%, with cities like Lucknow, Kanpur, and Ghaziabad being major urban centres. However, the rural population forms a significant majority, with 77.73% residing in villages.

In terms of infrastructure and services, around 94.70% of households own their homes, and a vast majority have access to banking services. However, access to the internet remains relatively low at 1.85%, though this is expected to improve with the expansion of telecom networks.

The state's economy and societal dynamics are changing, with increased interest in health and life insurance policies and rising literacy leading to greater participation in several sectors. Despite challenges, UP continues to play a crucial role in India's socio-economic fabric, with its capital, Lucknow, serving as a hub of administrative, cultural, and economic activity.

4 Historical Background

[5]Uttar Pradesh's history is deeply intertwined with the broader history of India, dating back thousands of years. Originally inhabited by the Aryans or the Dasas, who were primarily agrarian, the region saw the emergence of early civilisations. The Aryans laid the foundations of their civilisation in UP and produced significant literary works such as the Mahabharata, Ramayana, Brahmanas, and Puranas during their inhabitation.

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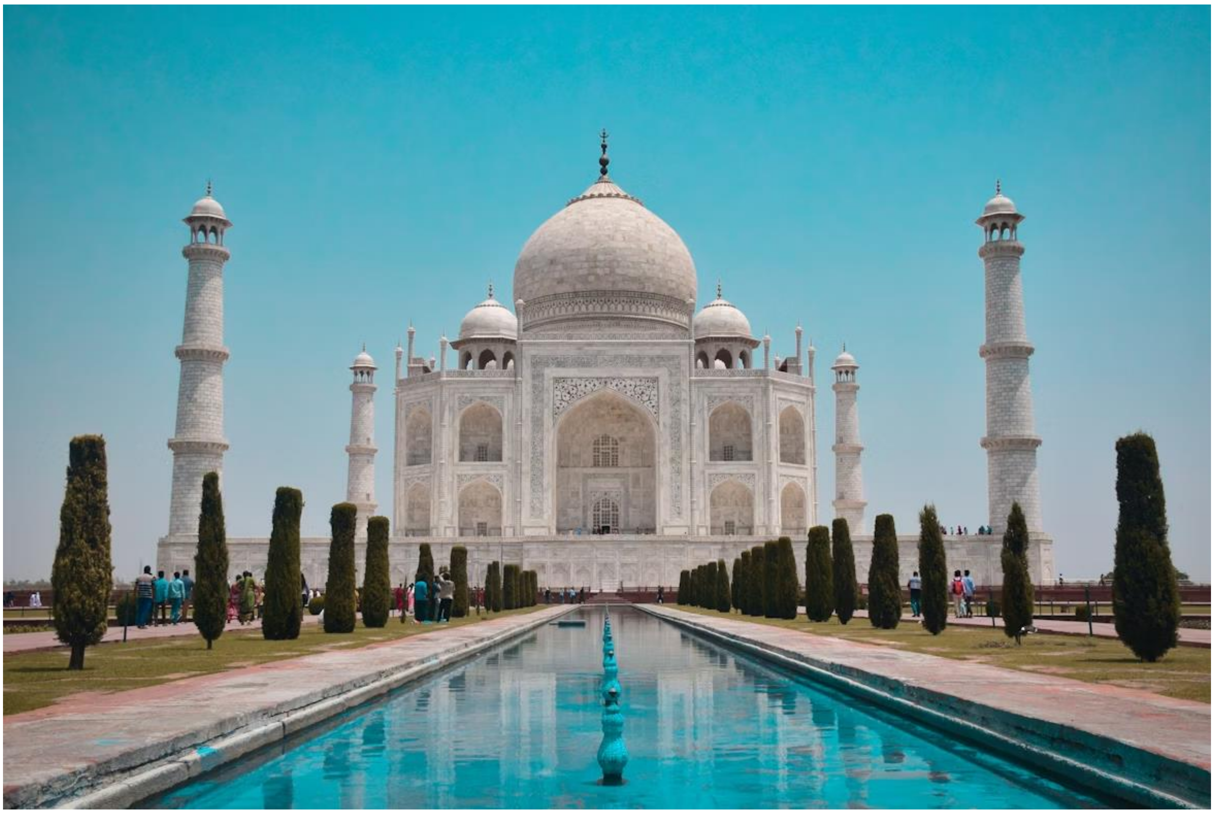
[5] Historical Background of UP

The state holds great significance in ancient Indian epics, with the Kosala kingdom of Ayodhya believed to be Lord Rama's birthplace and Mathura associated with the Mahabharata war.



[6]

Around the middle of the first millennium BC, Uttar Pradesh witnessed the advent of Lord Buddha and the spread of Buddhism. Sarnath, located in Uttar Pradesh, is where Lord Buddha delivered his first sermon, marking a significant moment in Buddhist history.

During the medieval period, UP saw the rise of Muslim rule, leading to the subjugation of local powers such as the Rajputs. The region reached its pinnacle of prosperity during the Mughal rule, particularly under Emperor Akbar.

The British East India Company established its presence in UP during the reign of the Nawabs of Awadh. UP played a crucial role in the Indian freedom movement, with significant contributions during the 1857 War of Independence.

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[6] Image credit

[7]

From the legendary rule of Rama to the British colonial era, UP has witnessed a rich tapestry of history, shaping its cultural, political, and socio-economic landscape over millennia.

5 Climatic Conditions[8]

Uttar Pradesh experiences a Mediterranean, hot summer climate, characterised by high temperatures and relatively low precipitation. With a mean elevation of 117.36 metres above sea level, the state's yearly temperature averages 29.43ºC, slightly higher than the national average. May marks the warmest month, with temperatures soaring up to 43ºC, while January is the coldest, with temperatures dropping to 11ºC. The state typically receives about 43 mm of precipitation annually, with July being the wettest month. Despite the hot and dry climate, humidity levels remain moderate, averaging around 45%. The weather conditions in UP facilitate various outdoor activities but also pose challenges of water scarcity and agricultural productivity.

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[7] Image credit

[8] Climatic Conditions

6 Economic Background of Area of Intervention[9]

Uttar Pradesh faces significant economic challenges that hinder its growth potential. Despite its vast population, UP's per capita income of Rs 70,792 for 2021-22 lags Pakistan's $1,588 per capita income, nearly double that of UP, and falls short of Sub-Saharan Africa's standards. The industrial sector's decline, with a growth rate plummeting from 9.9% (2012-17) to 0.6% (2017-22), highlights the state's economic struggles. Despite hosting investor summits, UP struggles with dismal conversion rates due to apprehensions regarding governance and law enforcement. Nearly 23% of UP's population lives in multidimensional poverty, with districts like Bahraich reporting poverty rates exceeding 70%. Health indicators mirror those of impoverished African nations, with high rates of anaemia among women and children. The Chief Minister's ambitious target of achieving a $1 trillion economy within five years requires an annual growth rate of 32%, surpassing the current growth rate of 8.28%. Without drastic reforms and a shift in focus towards income generation and quality of life, UP's economic revival remains elusive. UP's democratic process is marred by disenfranchisement and divisive issues, hindering efforts for economic transformation. Without addressing institutional shortcomings, and prioritising economic development over identity politics, UP's economic resurgence will remain stunted.

7 Objectives of the study

The evaluation of existing social security measures for individuals affected by leprosy in Uttar Pradesh reveals several challenges. Despite governmental policies and interventions, access to healthcare, education, employment, and societal inclusion remains limited due to stigma and discrimination. Awareness campaigns have had some impact, but societal perceptions still hinder integration. Utilisation rates of social security programs vary, with gaps in accessibility and reach. Actionable recommendations are needed to enhance these measures, focusing on improving accessibility, reducing stigma, and promoting inclusivity. Strategies for improved integration and advocacy efforts are essential to ensure the well-being and rights of affected individuals. Insights and data-driven recommendations will support policymakers and stakeholders in formulating inclusive policies and decision-making processes, ultimately fostering social security and inclusion for those affected by leprosy in Uttar Pradesh.

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[9] Economic Background

8 Design of the primary research

Geographical Focus

This study was conducted in Uttar Pradesh, focusing on TLM centres in Prayagraj, Barabanki, and Faizabad, where individuals affected by leprosy seek treatment. Additionally, the study included visits to several leprosy colonies in Mathura, Prayag, Lucknow, and Agra, providing a comprehensive understanding of the challenges faced by individuals affected by leprosy across different regions of the state.

Methodology

A mixed-method research approach was employed, combining both quantitative and qualitative methodologies to ensure a comprehensive understanding of the issue.

Participant Diversity

The participant pool was diverse, and included:

- Individuals directly impacted by leprosy and their families
- Social workers engaged in providing support to affected individuals
- Government officials responsible for implementing social security policies
- Collaborating with organisations and NGOs active in the field

Sample Size and Sampling Method

The study aimed to survey approximately 200 participants, including those affected by leprosy and their immediate family members, within UP. A multi-stage sampling approach was utilised, initially obtaining a list of leprosy-affected individuals from health records, followed by a random selection process. Stratified sampling ensured representation across various demographics.

Data Collection Methods

Surveys: Structured questionnaires gathered quantitative data from a representative sample.

- Interviews: Semi-structured interviews delved into personal experiences, challenges, and perceptions of individuals affected by leprosy, their families, healthcare professionals, and NGO officials.
- Focus Group Discussions (FGDs): Group discussions facilitated collective exploration of shared experiences and viewpoints among stakeholders.

Ethical Considerations

The study adhered to essential ethical principles, obtaining informed consent from all participants and prioritising privacy, dignity, and confidentiality throughout.

Data Analysis

Quantitative data from surveys underwent rigorous statistical analysis, employing tools such as mean, median, standard deviation, t-tests, ANOVA, and correlation to assess the efficacy of social security provisions.

Qualitative data from interviews and FGDs underwent thematic analysis, identifying recurring themes and patterns to gain deeper insights into participants' experiences, challenges, and suggestions for improvement.

9 Secondary Research

Secondary research serves as a foundational pillar in understanding the socio-economic landscape surrounding leprosy-affected individuals in Uttar Pradesh. It constitutes a meticulous exploration of various sources, including budgetary data, census records, reports on leprosy's status, and details about available social security schemes. The comprehensive nature of secondary research encompasses both; traditional mediums like newspaper articles and modern digital platforms such as online publications, government portals, and official census databases.

Budgetary data analysis provides insights into the financial allocations directed towards combating leprosy and supporting affected individuals. Census records offer demographic information, helping identify population segments most affected by the disease and their geographical distribution. Reports on leprosy's status provide crucial data on prevalence rates, treatment accessibility, and areas requiring targeted interventions. Information about existing social security schemes elucidates the support mechanisms available to affected individuals, including healthcare services, educational support, and rehabilitation programs.

The secondary research process involves rigorous data collection, analysis, and synthesis to generate a comprehensive understanding of the socio-economic challenges faced by individuals affected by leprosy in UP. By leveraging information from diverse sources, the research aims to identify gaps in existing support systems, assess the effectiveness of governmental policies and interventions, and propose actionable recommendations for enhancing social security measures. Insights derived from secondary research serve as a foundation for informed decision-making and policy formulation, aiming to improve the well-being and inclusion of leprosy-affected individuals in UP.

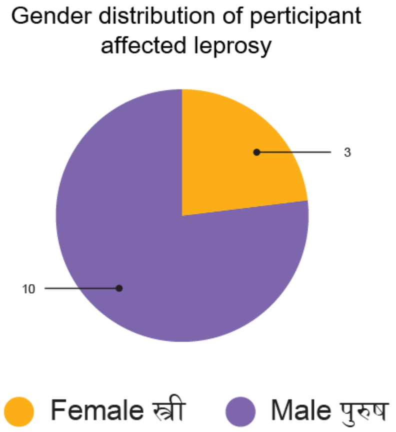
10 Data analysis

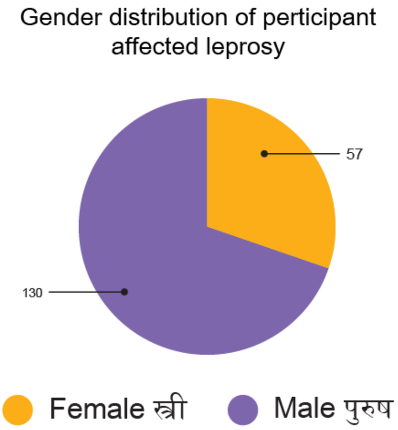
This section presents a detailed explanation of the data obtained through the research.

Demographic

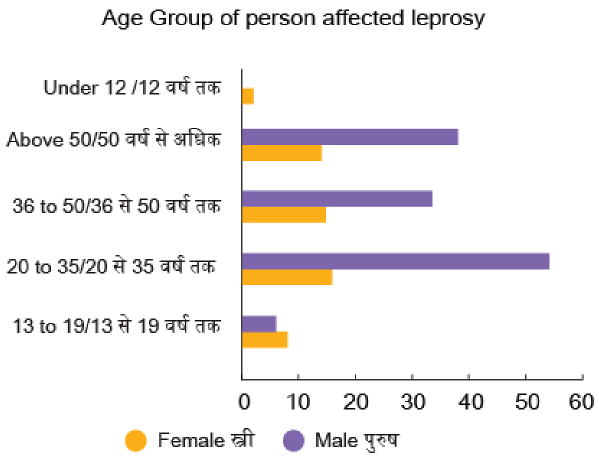
Gender Distribution and Age Groups

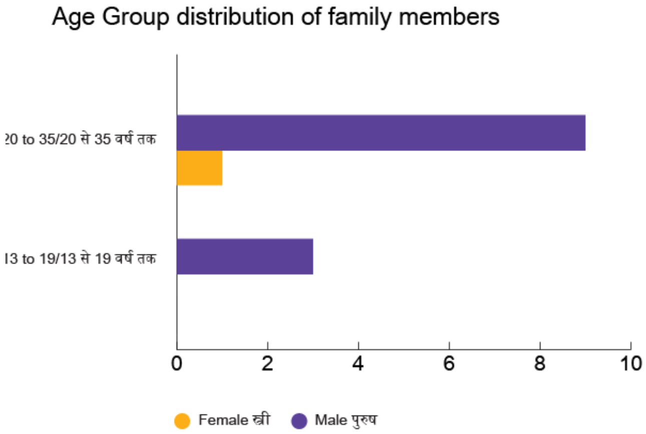
The research findings on the leprosy-affected population provide a comprehensive understanding of demographic characteristics, including gender distribution and age groups. Along with 187 participants with leprosy, 13 family members also took part in the survey. The gender distribution showed 60 female respondents (30%) and 140 male respondents (70%).


Gender distribution of perticipant affected leprosy


Gender distribution of perticipant affected leprosy

The age distribution revealed the prevalence of leprosy across various age groups. Under 12 years old, there were 2 female respondents (1.07%), while ages 13-19 comprised 6 males (3.21%) and 8 females (4.28%). Notably, the age group of 20-35 had 63 males (33.69%) and 19 females (10.16%). The groups aged 36-50 and above 50 also had significant numbers of affected individuals, with varying distributions between males and females.


Age Group of person affected leprosy


Age Group distribution of family members

The significant difference in the number of male and female participants can be attributed to several reasons encountered during the data collection. Firstly, cultural norms and family dynamics often restrict females from participating in such studies, especially when it involves disclosing personal health information like leprosy affliction. Many females reported that their partners or family members did not allow them to participate due to concerns about privacy and fear of social stigma. Additionally, some females expressed hesitation in talking about their condition or responding, citing discomfort and fear of judgment. Despite repeated efforts to encourage participation, several females remained reluctant, highlighting the persistent challenges of stigma and discrimination faced by women affected by leprosy.

[11]Status of Leprosy in India.

- National Progress: India reduced the prevalence of leprosy to less than 1 case per 10,000 population in 2005.
- Continued Challenges: India continues to face challenges, contributing to 60% of global new cases annually. Challenges include ongoing transmission in certain pockets, hidden cases within the community, stagnant detection rates since 2005, and rising disability rates due to delayed diagnosis.
- Innovative Strategies: The NLEP advocates a three-pronged approach, including Leprosy Case Detection Campaigns (LCDC), focused awareness campaigns in hot spots, and area-specific plans for hard-to-reach areas.
- Preventive Measures: Initiatives like post-exposure chemoprophylaxis (PEP) with single-dose rifampicin and the Mycobacterium Indicus Prani (MiP) vaccine are being explored to interrupt transmission and reduce disease burden.
- Challenges and Solutions: Challenges such as low voluntary reporting, stigma, and discrimination necessitate initiatives like the SPARSH Leprosy Awareness Campaign (SLAC) to promote awareness and reduce stigma. Additionally, reintroducing essential diagnostic services like skin smear examination is crucial.

Status of Leprosy in Uttar Pradesh.

- Burden of Disease: Being the most populous state, UP bears a significant burden of leprosy. Specific data on the current prevalence and incidence rates are not available.
- Implementation of NLEP: The NLEP strategies and plans are implemented by states, including UP. Efforts such as LCDC and awareness campaigns are being carried out in UP to address leprosy challenges.
- Challenges and Solutions: UP, like other states, faces challenges such as hidden cases, stigma, and delayed diagnosis. Efforts to address these challenges are aligned with national strategies.

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[11] National Centre for Biotechnology Information

- Data Availability: In the financial year 2020-2021*[*], Uttar Pradesh recorded 8,467 new leprosy cases, which increased to 10,560 cases in the next financial year.

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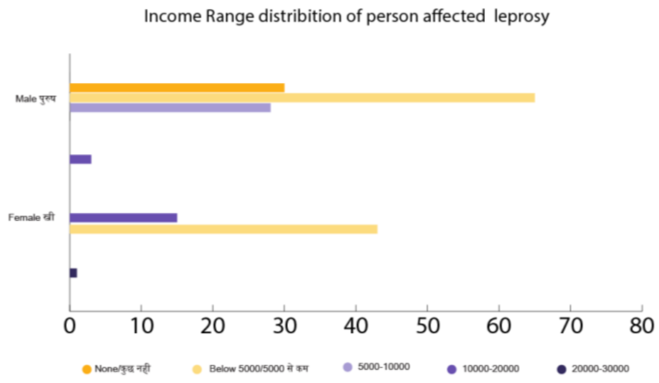
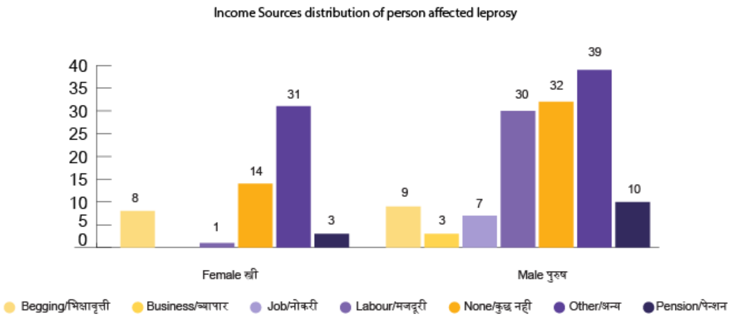
11 Income distribution and sources of livelihood

A noteworthy proportion had no income, with 14 females (7.49%) and 31 males (16.58%) falling into this category. The majority fell within the Below Rs 5000 income bracket, including 44 females (23.53%) and 71 males (37.97%). Individuals earning between Rs 5000-10000 were predominantly male (34, 18.18%). Higher-income brackets, such as Rs 10000-20000 and Rs 20000-30000 showed fewer respondents, and the income range of Over Rs 30000 was represented by a single male respondent.


Income Range distribibition of person affected leprosy

The research indicated varied means of livelihood for the leprosy-affected population. While some engaged in begging (11 males, 9 females), others secured jobs (8 males, 2 females), and a significant number were involved in agriculture (42 males, 32 females). The labour sector also played a crucial role, with 67 males (35.83%) and 12 females (6.42%) earning their livelihood through labour. Additionally, a few respondents, both male and female, relied on pensions for financial support.


Income Sources distribution of person affected leprosy

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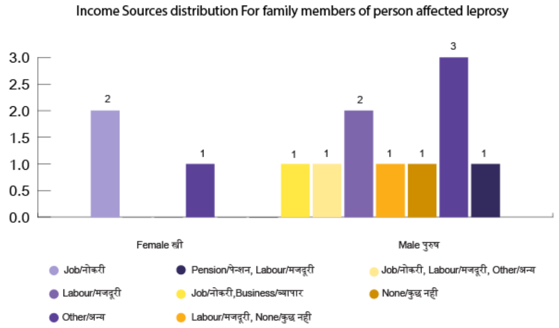
[*] Reference for the data: Unfortunately, the link from DGHS [https://dghs.gov.in/content/1329_1_Leprosy.aspx] has been removed.



[12]The study's findings on the pivotal role of education in shaping livelihood choices resonate strongly with the experiences of individuals like Anisha Devi. [13]Anisha's struggle to access education due to gender biases and economic constraints mirrors the challenges identified in the study. Despite her aspirations for formal employment, Anisha's limited educational opportunities hindered her ability to secure a job or start a business, relegating her to seeking alternative sources of income.

Similarly, [14]Radha Dubey's experience underscores the interconnectedness of education, employment, and entrepreneurship. Despite facing challenges due to her disability and social status, Radha's determination to pursue education and skills training reflects the transformative power of learning in overcoming barriers and achieving economic independence.

In conclusion, the study's findings, corroborated by real-life case studies like Anisha Devi and Radha Dubey, underscore the urgent need to address educational barriers and promote inclusive learning environments for individuals affected by leprosy. By prioritising education as a fundamental right and investing in targeted interventions to enhance access and quality, societies can empower marginalised communities to break free from cycles of poverty and exclusion, fostering inclusive socio-economic development for all.

12 Educational Background

A substantial proportion of respondents - 42 males (22.46%) and 28 females (14.97%) - had no formal education. Those with education below the 10th grade comprised 54 males (28.87%) and 15 females (8.02%). The data also showed varying levels of education, from 10th grade to post-graduation, with different distributions between males and females in each category. Overall, the research findings provide valuable insights into the diverse

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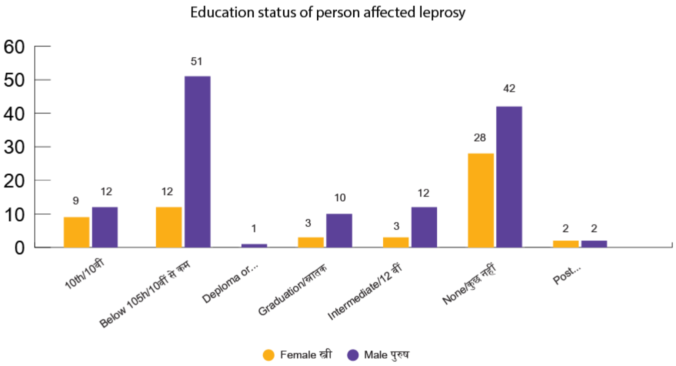
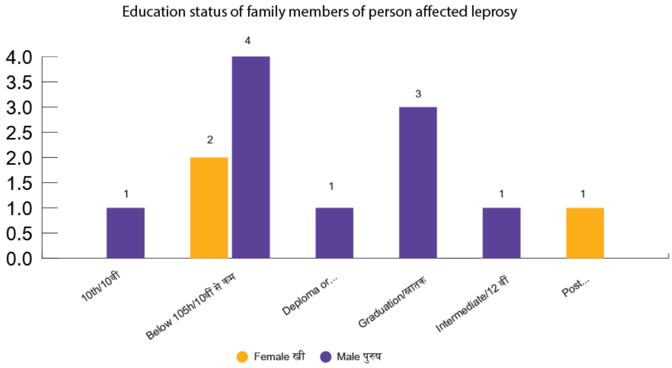
[12] Case studies
[13] Anisha Devi case study
[14] Radha Dubey case study





characteristics of the leprosy-affected population, shedding light on their socio-economic status and educational background.

The study's findings on disparities in educational attainment among individuals affected by leprosy, particularly females, are vividly exemplified in the real-life experiences of [15]Anisha Devi. Anisha's journey, marked by the obstacles she faced due to cultural norms and gender biases, mirrors the broader challenges highlighted in the study. Her struggle to access education due to societal expectations favouring male education resonates with the pervasive issue of limited opportunities for females affected by leprosy to pursue formal schooling.

Anisha's story underscores the critical need to address gender-specific barriers to education by challenging entrenched cultural norms and providing economic support to marginalised communities. Just as Anisha faced hurdles in accessing education opportunities beyond cultural barriers, individuals across similar contexts may encounter similar challenges, perpetuating cycles of poverty and exclusion.

Efforts to promote inclusive learning environments and empower individuals affected by leprosy, like Anisha, must prioritise initiatives that address gender disparities in education and combat societal stigma. By investing in programs that dismantle gender biases and create equal education opportunities, societies can unlock the potential of marginalised communities and pave the way for sustainable development and social justice.

Anisha's courageous journey serves as a poignant reminder of the urgent need to champion gender equality in education and ensure that all individuals, regardless of their circumstances, have access to quality education. Her resilience in the face of adversity inspires us to redouble our efforts in creating inclusive educational systems that empower individuals affected by leprosy and other marginalised communities to thrive and contribute meaningfully to society.

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[15] Case studies

[16]The government mandates that all educational institutions receiving funding or recognition must offer inclusive education for individuals affected by leprosy. This includes admitting students impacted by leprosy or those with affected family members without discrimination and providing them with appropriate education, sports, and leisure opportunities on par with others. Additionally, reasonable accommodations tailored to each student's needs must be provided, along with support to maximise their academic and social development. Monitoring their participation and progress is also required.

Children over six years old affected by leprosy who have not been admitted or could not complete elementary education must be admitted in an age-appropriate class and are entitled to special training under the Right of Child to Free and Compulsory Education Act, 2009.

Government institutions at all levels of education must reserve seats for individuals affected by leprosy as per the Right of Persons with Disabilities Act, 2016. However, affected individuals are still eligible to compete for seats not reserved for them. The reservation also extends to leprosy-cured persons with benchmark disabilities, including those who have undergone the first dose of MDT.

Awareness of these policies and the importance of education is essential to reach communities affected by leprosy, particularly in areas lacking an educational culture or unaware of existing policies. Educational outreach programs can inform affected individuals and their families about their rights to education and emphasise the significance of education for personal development, social integration, and overall well-being. By fostering a culture of education and awareness, we can empower individuals affected by leprosy to access the educational opportunities they are entitled to and support them in completing their education successfully.

13 Awareness of Social Security Schemes

152 respondents (81.3%) were aware of the Ayushman Bharat Yojana. 134 respondents (71.7%) reported familiarity with the Antyodaya Card Scheme. The awareness of the Leprosy Pension Scheme was noted among 83 individuals (44.4%). 21 respondents (11.2%) were aware of other pension schemes. 118 respondents (63.1%) were aware of the Pradhan Mantri Awas Yojana (PMAY).

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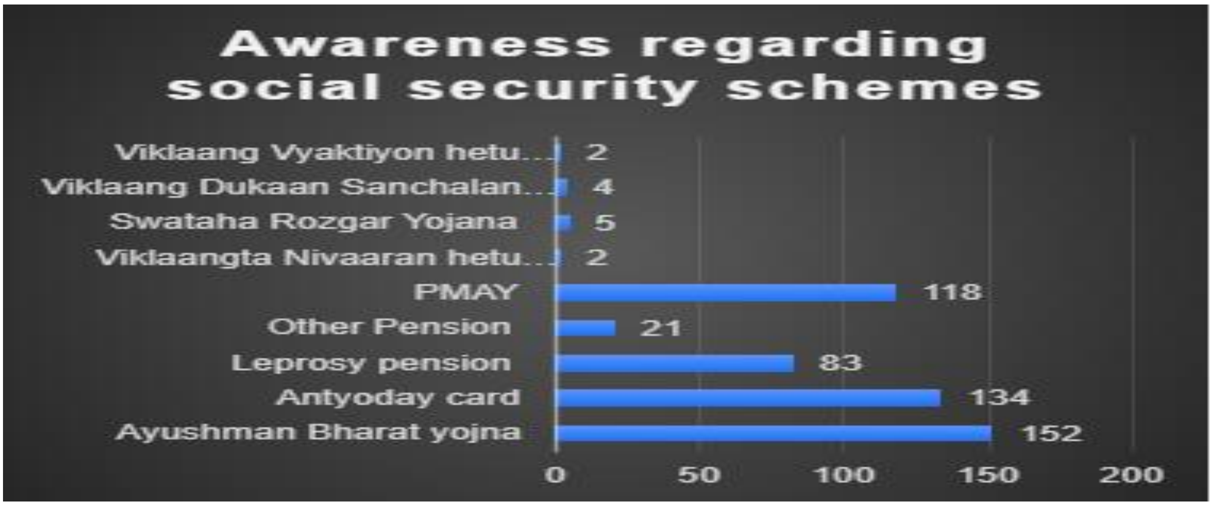
[16] Page 11 Chapter 3

However, only two individuals each were aware of the Viklangta Nivaaran Hetu Shalya Chikitsa Anudan Scheme and the Viklang Vyaktiyon Hetu Banavati Ang Scheme. Five respondents recognised the Swataha Rozgar Yojana, while four were aware of the Viklaang Dukaan Sanchalan Rinn Yojana. These findings indicate varying levels of awareness among respondents regarding different government schemes, reflecting the diverse nature of social welfare programs in place.



The study's findings on varying levels of awareness regarding government social welfare schemes resonate deeply with the diverse narratives of individuals like Sundara Devi, Fani Mahato, Radha Dubey, and others who have confronted multiple challenges in accessing essential support systems.

[17]Sundara Devi's journey - marked by the struggles of a woman affected by leprosy in rural West Bengal - mirrors the barriers many face in understanding and accessing government assistance. Just as Sundara grappled with societal stigma and bureaucratic hurdles in her quest for healthcare, individuals across different regions may encounter similar challenges due to limited awareness of available schemes.

Similarly, Fani Mahato's story sheds light on the impact of social stigma and physical disabilities on an individual's ability to access government support. Despite benefiting from certain welfare schemes, Fani's exclusion from others due to his missing fingers underscores the need for more inclusive policies and targeted outreach initiatives to ensure that all eligible individuals receive assistance.

Radha Dubey's experience highlights the intersectionality of challenges faced by young women in rural areas, from limited education opportunities to societal stigma surrounding health issues like leprosy. Her struggle to find acceptance and support amidst societal

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[17] Case studies

prejudices reflects the broader need for awareness programs and advocacy efforts to promote inclusivity and eliminate discrimination.

In conclusion, the study underscores the urgent need for comprehensive and inclusive communication strategies to bridge the gap between policy intent and ground realities. By drawing insights from diverse case studies like Sundara, Fani, and Radha, policymakers can better understand the nuanced barriers individuals face in accessing government support and tailoring interventions to address their specific needs. Through targeted outreach, advocacy, and awareness programs, we can empower marginalised communities to overcome obstacles and access the support they need to lead dignified and fulfilling lives.

The proposed bill mandates the implementation of awareness programs to educate various stakeholders about leprosy-related issues, including education, social security, and the disease itself. Here's how awareness programs are addressed in the bill.

1. Training and Awareness Programs [18] (Section 24): The appropriate Government is required to conduct and promote suitable training and awareness programs for healthcare providers, public servants, and members of the general population. These programs are designed to emphasise the importance of early treatment of leprosy and dispel misconceptions surrounding the disease. They may include educational components focused on various aspects of leprosy, including its causes, symptoms, treatment options, and preventive measures.
2. Promotion of Education (Various Sections): While the bill does not explicitly mention awareness programs tailored to education, the overall emphasis on social inclusion and rehabilitation suggests that educational aspects would likely be covered in the broader awareness initiatives. These programs may promote access to education for persons affected by leprosy, raise awareness about their right to education, and address any stigma or discrimination they may face in educational settings.
3. Social Security Awareness (Section 21): The bill mandates the appropriate Government to promulgate schemes and programs to safeguard and promote the rights of persons affected by leprosy and their family members, including access to social security. Awareness programs may be part of these schemes, providing information about available social security benefits, eligibility criteria, application procedures, and the rights of affected individuals.
4. Healthcare Awareness (Section 22): Awareness programs may also cover various aspects of healthcare related to leprosy. For example, programs may educate individuals about the importance of barrier-free access to healthcare facilities, the rights of persons affected by leprosy during medical treatment, the availability of free-of-cost MDT, and measures to prevent the spread of leprosy.

Overall, the bill emphasises the importance of awareness programs in addressing various leprosy-related issues, including education, social security, and healthcare. These programs

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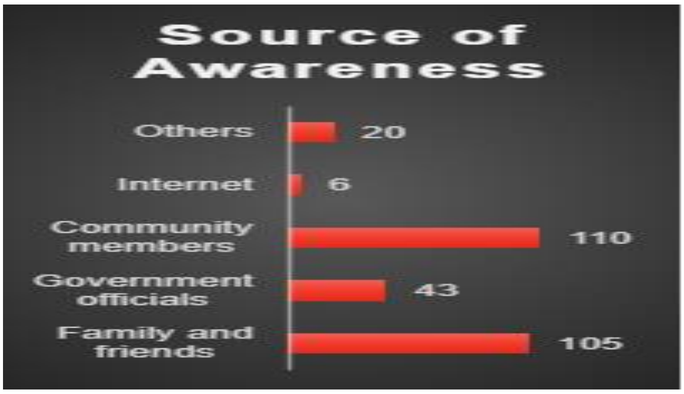
[18] References of policies

play a crucial role in dispelling myths, reducing stigma, promoting rights, and facilitating the social inclusion and well-being of persons affected by leprosy and their families.

14 The Source of Awareness of Government Schemes



The study findings illustrate the diverse sources through which respondents gain awareness of government schemes. A significant proportion constituting 105 individuals (56.1%), rely on family and friends as their primary source of information. This underscores the pivotal role of informal networks and interpersonal communication in disseminating knowledge about social welfare programs. Government officials serve as a source of awareness for 43 respondents (23%), highlighting the importance of direct communication from official channels in reaching the public. Community members contribute significantly to awareness, with 110 respondents (58.8%) citing them as a source, emphasising the role of community engagement and word-of-mouth communication. A smaller but notable group of 6 respondents (3.2%) rely on the internet for information, indicative of the increasing trend of online platforms in accessing government scheme details. Furthermore, a diverse category of sources including print media, NGOs, and doctors contribute to awareness for 20 respondents (10.7%), reflecting the impact of external entities in reaching specific segments of the population. This comprehensive breakdown of awareness sources highlights the need for policymakers to understand and leverage these channels effectively to ensure the widespread dissemination of information about social welfare initiatives.

15 Documentation Status

The provided data outlines the documentation status of respondents for various official documents. Here is an overview of the numbers associated with each type of document.

1. Aadhaar Card: 187 (100%)

   All 187 respondents possess an Aadhaar Card, indicating full compliance with the government's initiative to provide a unique identification number to residents.

2. Medical Evidence of Leprosy: 129 (69%)

   A significant majority of 129 respondents possess medical evidence confirming their leprosy condition, crucial for accessing health services and benefits.

3. Domicile Certificate: 89 (47.6%)

   Domicile Certificates, establishing an individual's residence, are held by 89 respondents, often required for availing local government services.

4. Income Certificate: 92 (49.2%)

   Income Certificates, verifying an individual's income level, are held by 92 respondents, essential for determining eligibility for government welfare schemes.

5. Caste Certificate: 83 (44.4%)

   Caste Certificates, indicating an individual's social group, are possessed by 83 respondents, often required for availing caste-based reservations and benefits.

6. Disability Certificate: 65 (34.8%)

   65 respondents have a Disability Certificate, crucial for accessing disability-related benefits and services.

7. Voter Card: 127 (67.9%)

   A substantial number of respondents, 127, possess a Voter Card, serving as proof of identity for voting.

8. UDID Card: 54 (28.9%)

   The Unique Disability ID (UDID) Card, facilitating access to disability-related services, is held by 54 respondents.

9. Ayushman Card: 70 (37.4%)

   70 respondents possess an Ayushman Card, providing access to health insurance benefits.

10. PAN Card: 105 (56.1%)

    The Permanent Account Number (PAN) Card, essential for financial transactions, is held by 105 respondents.

11. BPL Card: 45 (24.0%)

    45 respondents possess a Below Poverty Line (BPL) Card, indicating eligibility for certain government welfare programs.

The study's findings on the possession of official documents among respondents provide valuable insights into access to essential services and benefits for individuals affected by leprosy. These findings resonate with real-life challenges faced by individuals [19]like Sundara Devi, Manju Ghoshal, Radha Dubey, and others, highlighting the importance of documentation in navigating bureaucratic processes and accessing government support programs.

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[19] Case studies

The widespread possession of key identification documents, such as Aadhaar, Voter, and PAN cards, reflects the success of government initiatives in promoting universal identification. This mirrors the experiences of individuals like Manju Ghoshal, who benefit from schemes like Leprosy Pension and Ayushman Bharat, due to their possession of essential documents.

However, the disparities in possession rates for specific documents, such as disability certificates and domicile certificates, mirror the challenges individuals like Radha Dubey face in accessing targeted benefits and services. Limited awareness, administrative hurdles, and social stigma contribute to lower possession rates for these critical documents, hindering individuals' ability to access the support they need.

Addressing these disparities must include targeted interventions to enhance awareness, streamline administrative processes, and combat stigma. Initiatives like those advocated by Sundara Devi, who fought for policy changes and improved healthcare services for marginalised communities, are essential to ensure equitable access to services and benefits for all individuals affected by leprosy.

By addressing the underlying reasons for disparities in document possession and implementing inclusive policies and programs, societies can empower individuals like Radha Dubey to navigate bureaucratic processes with ease and access the support they need to lead dignified lives. These findings underscore the importance of ongoing efforts to promote inclusivity, combat stigma, and ensure that no one is left behind in accessing essential services and benefits.

16 Challenges in Awareness

This data provides insights into the various challenges individuals encounter in obtaining documentation, with an emphasis on awareness-related issues. Here is an elaboration of each challenge along with its corresponding percentage:

1. Lack of Awareness: 150 (80%)
   The predominant challenge reported by 80% of respondents is a lack of awareness. This suggests a widespread need for educational initiatives to inform individuals about the importance and procedures of obtaining documentation.

2. Corruption: 20 (11%)
   Corruption was a challenge for 11% of respondents, indicating the presence of corrupt practices that hinder the fair and transparent issuance of documents.

3. Limited Mobility: 128 (68%)
   Limited mobility is a significant challenge for 68% of respondents, highlighting difficulties individuals face accessing government offices or documentation centres due to physical disabilities or transportation constraints.

4. Legal or Citizenship Status: 5 (3%)
   Legal or citizenship status issues were reported by 3% of respondents, indicating challenges related to legal documentation that may affect certain individuals' ability to obtain specific documents.

5. Political Instability: 14 (7%)
   Political instability poses challenges for 7% of respondents, suggesting disruptions in the documentation process due to unstable political environments.

6. Discrimination or Bias: 40 (21%)
   Discrimination or bias is cited as a challenge by 21% of respondents, indicating discriminatory practices that hinder certain individuals' access to documentation based on factors like caste, gender, or ethnicity.

7. Disabilities or Health Issues: 20 (11%)
   Disabilities or health issues are reported by 11% of respondents, highlighting the additional barriers faced by individuals with health challenges in navigating the documentation process.

8. Lack of Documents: 91 (49%)
   The lack of necessary documents is a significant challenge for 49% of respondents, indicating gaps in documentation that impede individuals' access to government services or benefits.

9. Geographic Barriers: 21 (11%)
   Geographic barriers were cited by 11% of respondents, indicating challenges related to living in remote or difficult access areas that affect the documentation process.

10. Language Barriers: 15 (8%)
    Language barriers were identified by 8% of respondents, suggesting that language differences pose challenges in understanding and completing the documentation process.

The pervasive challenge of lack of awareness highlighted by 80% of respondents mirrors the struggles faced by individuals like Sundara Devi, [20]Manju Ghoshal, and Radha Dubey in accessing essential services due to limited understanding of documentation processes. Sundara's journey through bureaucratic hurdles and societal stigma underscores the critical need for educational initiatives to inform individuals about documentation procedures, empowering them with the necessary information to navigate bureaucratic processes.

Similarly, the issue of corruption reported by 11% of respondents echoes the challenges faced by individuals like Fani Mahato and Anisha Devi, who encountered obstacles in accessing government support due to corrupt practices. Fani's experience of being removed from social welfare programs due to missing fingers and Anisha's struggle to access government aid due to incomplete documentation highlight the detrimental impact of corruption on individuals' ability to obtain essential documents and access support services.

Addressing these multifaceted challenges requires targeted interventions and systemic reforms, as advocated by [21]Sundara, Manju, Radha, Fani, and Anisha. Efforts to enhance awareness, combat corruption, and streamline documentation processes are essential to ensure equitable access to services for all individuals, regardless of their socio-economic status or background.

By learning from the experiences of individuals affected by leprosy and other marginalised communities, policymakers can develop more inclusive and effective strategies to empower individuals to exercise their rights and access essential services. These findings underscore the importance of ongoing efforts to address barriers to documentation and promote inclusivity in government processes, ultimately advancing social justice and equality for all.

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[20] Case studies

[21] Case studies

17 Social Security Uptake Among Leprosy-Affected Individuals

The report provides a comprehensive overview of the utilisation of various social security schemes by individuals affected by leprosy. Here are the key findings.

70 respondents benefitted from the Ayushman Bharat Yojana, which aims to provide financial protection for medical expenses. Additionally, 21 respondents received the Leprosy Pension, indicating targeted financial support for those affected by the disease.

The PMAY, focusing on affordable housing, sees participation from only 10 individuals. However, 20 respondents are actively involved in the NLEP, showcasing their engagement to control and eradicate leprosy.

The study's findings on the varying levels of participation in social welfare programs among individuals affected by leprosy resonate with the experiences of individuals like Sundara Devi, Anisha Devi, and others facing similar challenges.

[22]Sundara Devi, hailing from a small village in Purulia, West Bengal, struggled to access essential support systems despite being eligible for government aid. Her journey reflects the importance of awareness and outreach initiatives to ensure that individuals like her are aware of available social welfare schemes.

Similarly, Anisha Devi's story underscores the significance of addressing barriers to participation in these programs. Despite facing economic constraints and societal stigma, Anisha's resilience highlights the potential impact of social welfare schemes in improving the lives of individuals affected by leprosy.

Moreover, the experiences of individuals like Manju Ghoshal and Radha Dubey shed light on the complexities of accessing social welfare programs. Limited awareness, administrative hurdles, and societal stigma are common barriers that hinder the ability to benefit from available schemes.

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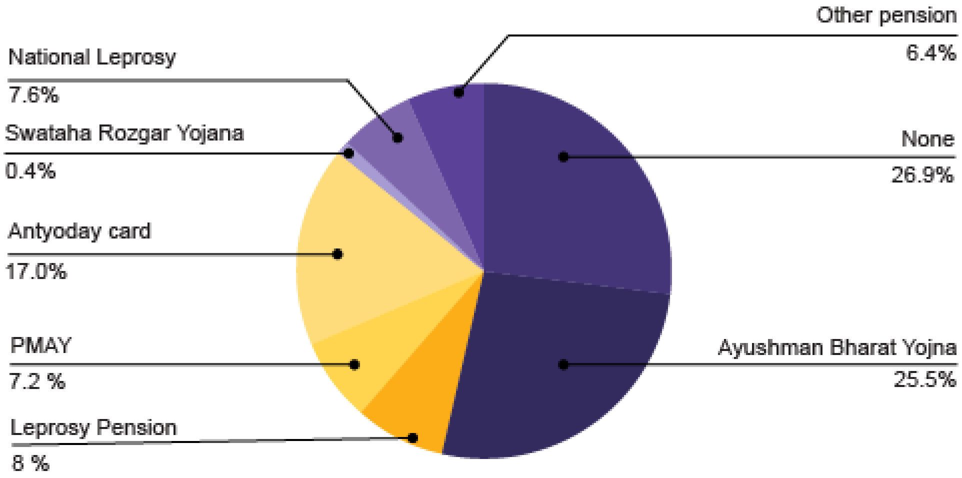
[22] Case studies



In conclusion, the study's findings underscore the urgent need for targeted outreach efforts and streamlined processes to ensure equitable access to social welfare programs for individuals affected by leprosy. By addressing these barriers, policymakers can empower marginalised communities to access the support and resources needed to lead dignified lives.

18 Challenges in Obtaining Benefits from Social Security

The main challenges reported by respondents in accessing benefits from social security schemes provided by the Central or State government are diverse and multifaceted.

They include Lack of Awareness (163 respondents), Digital Literacy (152), Inadequate Documentation (140), Complex Eligibility Criteria (109), Lack of Transparency (46), Geographic Accessibility (25), Political Factors (25), Corruption (14), Language Barrier (13) and Social Stigma (11). Understanding these challenges is crucial for policymakers to address barriers and enhance the effectiveness of social security programs, ensuring they reach and benefit a broader population.

19 Impact of Access to Social Security Benefits

The data provides valuable insights into the impact of access to social security benefits on overall quality of life for individuals, categorised by gender. Examining the responses, it is evident that most females reported significant improvements in their quality of life, with 17 respondents expressing this positive outcome. This suggests that the availability of social security benefits has had a notable positive effect on the well-being of many females.

Similarly, among males, 54 respondents reported significant improvement in their overall quality of life due to access to social security benefits. This underscores the importance of such programs in positively influencing the lives of males.

Furthermore, a significant number of females (25 respondents) and males (36 respondents) reported a neutral impact on their quality of life. This suggests that, for a significant portion of the respondents, access to social security benefits did not lead to a noticeable improvement or decline in their overall well-being.

On the other hand, a smaller number of females (5 respondents) and males (16 respondents) indicated a slight improvement in their quality of life. While the improvement may not be as pronounced as in the Significant Improvement category, it signifies a positive influence on their well-being.

Lastly, a few females (3 respondents) and males (2 respondents) reported sufficient improvement in their overall quality of life. This indicates that, while the impact may not be drastic, there is a perceptible positive change for this group of respondents.

[23]Social Inclusion, Healthcare and Rehabilitation (Chapter V)

1. Enhanced Livelihood Opportunities: Access to social security benefits for persons affected by leprosy and their families can significantly enhance their livelihood opportunities. Financial assistance for income-generating activities and vocational training provided under the bill can empower them to become economically self-sufficient.

2. Poverty Alleviation: Social security benefits such as pensions and unemployment allowances can alleviate poverty among persons affected by leprosy who may face challenges in securing employment due to stigma and discrimination. This financial support can help meet their basic needs and improve their overall quality of life.

3. Healthcare Access: Improved access to social security benefits can also facilitate better healthcare access for persons affected by leprosy. By covering medical expenses and therapeutic interventions through comprehensive insurance schemes, the bill ensures timely and adequate treatment without financial burden.

4. Dignity and Social Inclusion: Social security benefits play a crucial role in restoring the dignity and social inclusion of persons affected by leprosy. By providing them with financial support and access to essential services, the bill helps counteract the social stigma and discrimination they often face, enabling them to participate more fully in society.

5. Empowerment of Vulnerable Groups: Vulnerable groups within the leprosy-affected community, such as those without families or shelter, can benefit significantly from social security provisions. Financial assistance and support services tailored to their needs empower them to rebuild their lives and integrate into mainstream society.

6. Reduction of Health Disparities: Access to social security benefits can contribute to reducing health disparities among persons affected by leprosy. By ensuring equitable access to healthcare facilities and services, the bill promotes health equity and helps address the disproportionate burden of disease faced by this marginalised population.

7. Long-term Socio-economic Stability: Social security benefits provide a safety net for persons affected by leprosy, offering them stability and security in the face of economic hardships. By promoting long-term socio-economic stability, the bill enables them to plan and pursue their aspirations with confidence.

In conclusion, the inclusion of social security benefits in the bill has the potential to have a transformative impact on the lives of persons affected by leprosy, offering them financial security, access to essential services, and opportunities for socio-economic advancement. By addressing the challenges they face, the bill contributes to fostering a more inclusive and equitable society for all.

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[23] Social Inclusion, Healthcare and Rehabilitation (Chapter V)

20 Community's Attitude Towards Individuals Affected by Leprosy

This data reveals insights into the community's attitudes towards individuals affected by leprosy, categorised by gender. Responses indicate a spectrum of perceptions.

1. Negative: Among females, 3 respondents reported negative attitudes, while 20 males expressed similar sentiments.

2. Very Negative: 6 females and 23 males indicated very negative attitudes.

3. Neutral: Most respondents - 43 females and 73 males - expressed neutral views towards individuals affected by leprosy.

4. Positive: 4 females and 6 males reported positive attitudes.

5. Very Positive: Only 1 female and 8 males expressed very positive attitudes.

The study's findings regarding community attitudes towards individuals affected by leprosy align with the need for awareness campaigns and educational initiatives to address stigma and foster inclusivity. Real-life cases like [24]Sundara Devi's journey underscores the importance of combating misconceptions and negative perceptions within the community. Despite facing rejection and isolation due to leprosy-related stigma, Sundara's resilience and advocacy efforts highlight the transformative impact of fostering a more positive and empathetic community attitude.

Similarly, [25]Manju Ghoshal's experience reflects the challenges posed by negative attitudes towards individuals affected by leprosy. Despite receiving government support, Manju encountered social stigma and discrimination, emphasising the urgent need for community-level interventions to promote acceptance and understanding.

In conclusion, the study's findings, supported by real-life case studies, underscore the critical importance of addressing negative perceptions and fostering a more supportive community attitude towards individuals affected by leprosy. By implementing targeted awareness campaigns and educational initiatives, societies can challenge misconceptions, reduce stigma, and create inclusive environments where all individuals can live with dignity and respect.

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[24] Case studies

[25] Case studies

21 Findings

1. High Incidence of Leprosy: India has one of the highest numbers of new leprosy cases globally, with 103,819 new cases reported every year.

2. Discrimination and Stigma: Persons affected by leprosy and their families face severe discrimination and stigma, leading to segregation, restrictions, and exclusions within communities and public spaces.

3. International Recognition: The United Nations General Assembly recognised the marginalisation of persons affected by leprosy and their families, emphasising the need for protections and provisions to ensure their rights and welfare.

4. Legal Framework Gaps: While the Rights of Persons with Disabilities Act, 2016 addresses some issues, it falls short of covering all persons affected by leprosy. Discriminatory provisions in various civil and criminal laws perpetuate stigma and exclusion.

5. Need for Anti-discrimination Measures: Affirmative action and anti-discrimination measures must extend to all persons affected by leprosy, including those undergoing treatment or undiagnosed, as well as their family members.

6. Repeal of Discriminatory Laws: There is a pressing need to repeal or amend discriminatory provisions in existing laws that perpetuate stigma and segregation based on outdated beliefs about leprosy.

7. Inadequate Implementation: Previous recommendations, such as those from the Law Commission of India, have seen little to no action, indicating gaps in implementation and enforcement.

22 Recommendations

1. Comprehensive Anti-discrimination Legislation: Enact a comprehensive law to eliminate discrimination against persons affected by leprosy and their families, addressing gaps left by existing legislation.

2. Awareness and Education Campaigns: Launch nationwide awareness and education campaigns to dispel myths and misconceptions about leprosy, promoting early treatment and social inclusion.

3. Capacity Building: Provide training and capacity-building programs for healthcare providers, public servants, and the general population to improve understanding and treatment of leprosy.

4. Legal Reforms: Repeal or amend discriminatory provisions in civil and criminal laws that perpetuate stigma and segregation based on leprosy diagnosis.

5. Community Rehabilitation Programs: Implement community-based rehabilitation programs to support the social inclusion and economic empowerment of persons affected by leprosy and their families.

6. Monitoring and Evaluation: Establish mechanisms for monitoring and evaluating the implementation of anti-discrimination measures, with regular reporting to track progress and identify areas for improvement.

7. International Cooperation: Collaborate with international organisations and bodies to exchange best practices and resources for combating leprosy-related discrimination on a global scale.

23 Annexures

- Qualitative questionnaire
- Quantitative questionnaire
- Case studies
- Literature review
- Rajya Sabha Bill
- National Centre for Biotechnology Information
- World Health Organisation
- Up Tourism
- Climate history UP
- Census UP 2011
- The Wire Report
- NLEP Annual Report

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