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## Political Participation and Its Impact on Inclusive Governance: A Study on Leprosy Affected People of West Bengal

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### ABSTRACT

Leprosy, a chronic infectious disease which predominantly affects the skin, nerves, and limbs, has long been associated with stigmatization and discrimination. The disease leads to the marginalization of affected individuals in different domains of society, including political awareness as well as political participation. The study explores the crucial issue of political inclusion and participation of leprosy affected people. It studies the barriers to political participation of these people, including social stigma, discrimination, limited access to education and health care and legal obstacles. It further sheds light on the adverse impact of these barriers on their ability to engage in political activities such as exercising adult franchise, running for office, and voicing their concerns. The study delves into the challenges faced by leprosy affected people in engaging with political processes and institutions, while highlighting the significance of their participation for promoting social justice, human rights, and inclusive governance. It emphasizes the need to address societal prejudices and create an enabling environment that empowers this marginalized group to exercise their political rights.

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### Introduction

Leprosy, also known as Hansen's disease, is a chronic infectious disease caused by the bacterium *Mycobacterium Leprae*. It affects the skin, peripheral nerves and other organs. If not treated early it can



result in significant physical disabilities. Leprosy has affected millions of people worldwide, leading to physical disabilities, social stigma, and marginalization. It is a major public health problem in some low-resource countries and India accounts for over 60% of the global leprosy burden (World Health Organization, 2016)<sup>1</sup>. Though India declared herself as a leprosy-free country in 2005 but till now India is residence to 60% of the World's leprosy patients. According to National Leprosy Elimination Programme (NLEP) report, 9,175 leprosy cases were on record in West Bengal only in 2017-2018.<sup>2</sup> Despite several efforts to eliminate leprosy as a public health problem, it continues to effect vulnerable population, including marginalized communities such as those affected by leprosy.

In spite of significant advancement in medical treatment, the leprosy-affected individual continues to face social, economic, and political challenges besides physical challenges. The social stigma associated with leprosy often leads to discrimination, isolation, and exclusion from mainstream society.<sup>3</sup> This can also impact the political awareness and participation of the individuals affected by leprosy as well as whole leprosy affected people's community. They may also face barriers to their political participation, limiting their ability to advocate for their rights and influence policy decisions. The study delves into the historical context, tracing the roots of discrimination against leprosy-affected individual and the impact on their ability to engage in political process. It highlights the deep-seated misconceptions, myths, and fears associated with leprosy that have perpetuated social exclusion, making it difficult for this community to actively participate in politics. People develop and express their opinion about the world and how it is governed, and take part in the decision making process through political participation. Everyone, including people affected by leprosy or disability, has the right to participate in the political process. The Convention on the Rights of Persons with Disabilities (CRPD, 2006), article 29 (on participation in political and public life) stated that "States parties shall guarantee to person with disabilities political rights and the opportunity to enjoy them on an equal basis with others".<sup>4</sup>

### **Literature Review:**

Conduct an extensive review of existing academic and non-academic Literature to identify the barriers and challenges faced by the leprosy community in political participation. This will involve examining case studies, policy documents, legal frameworks, and previous research in related areas.

**I. M Alam, M Yunus, A Kalam (1997)** in their edited book 'Social Stigma in Leprosy' had discussed about the social stigma which have to face the leprosy affected individual.



II. **JT Jacob, C Franco-Paredes (2008)** in their article have explored different approach of awareness programme from ancient India to Modern India.

III. **A.K. Sinha and B.G. Banerjee** in their edited book have discussed leprosy affected individual from the socio cultural perspective.

IV. **S N Brody (1974)** in his book have discussed about the ability to create social relationship of the leprosy affected persons.

V. **S Ahmad and V M Katoch** in their article explained the social well-being of leprosy affected people.

VI. **M S Raju** in his doctoral thesis he explored the communication process of different organizations and changing behavior towards the leprosy affected persons.

VII. **Ghimire & Madan (2003)** in their article briefly discussed marginalization of leprosy affected individual from socio cultural and economic dimension.

VIII. **P Govindharaj, S Srinivasan and J Darlong(2018)** in their article has broadly discussed the social participation and the factors associated with it.

IX. The Leprosy Mission Trust of India (2020) in their article had discussed about political participation of leprosy affected people.

X. **J Susan Hansdak** in her work “Cultural Explanation of a chronic disease leprosy” had focused on the cultural aspect of the community.

XI. **N. Jemimah** in her work she discussed about the community studies of leprosy affected peoples of Andhra Pradesh.

XII. **Apalak Das** in his doctoral thesis he brings out the scenario of the disease leprosy and colonies of leprosy affected individual.

In view of the fact that various scholar had discussed either social participation or the socio-cultural and economic condition of the individual affected by leprosy. Various scholars worked on political participation of different Tribal community of different districts of India. But there are only a few organizations who promote political awareness and political participation of leprosy affected individuals and there is a little literature on this subject. The proposed study tries to find out the barriers and challenges had to face the leprosy affected individual and try to understand strategies and intervention to



enhance the political inclusion of leprosy affected individual. Furthermore the proposed study will discuss potential benefits of increasing political awareness and participation for the leprosy community including better access to healthcare, social well-being and other entitlements.

### **Objectives of the study**

- I.** To identify the specific barriers and challenges that hinder the political participation of the leprosy affected individual.
- II.** To explore the social, cultural and legal factors contributing to the marginalization of the people affected by leprosy.
- III.** To analyze existing initiatives, policies and legal frameworks aimed at promoting political participation and inclusion of marginalized communities.
- IV.** To develop political recommendation and strategies to enhance the political participation of the leprosy affected individual.
- V.** To examine the current political participation levels of leprosy affected people in West Bengal.

### **Concept of political participation**

The concept of political participation is crucial in maintaining a healthy and functioning democracy. It ensures that citizen have role in shaping the policies and decisions that impact their lives and provides a mechanism for holding elected official accountable. International encyclopaedia of Social Science(Vol.XII) defines Political Participation as ‘‘These voluntary activities by which members of a society share in the selection of rulers directly or indirectly in the formation of public policy’’.<sup>5</sup> Political participation refers to the various activities and action undertaken by individual and groups to influence or contribute to the decisions making processes and governance of a society or a political system.<sup>6</sup> Political participations can take numerous forms, ranging from traditional to modern methods. Some common examples include: voting, political campaigning, protest and demonstrations, engaging in public forum, petition signing, social media activism, contributing to political discourse etc.<sup>7</sup> Both national governments and the United Nations (UN) have developed frameworks and initiatives to promote their rights and political awareness. Political participation is closely associated with political awareness; in fact this is the very basis of political participation. Political awareness is nothing but perception and beliefs about politics such as, the constitution of his country, problems facing by the country, various political issues etc. Political participation is a basic concept in political science and scholars define the concept in



different ways. It may be defined as the actions of citizens seeking to influence or support Government and politics.<sup>8</sup> Political participation for any group or individual, society, community is one of the most essential elements to develop and express their opinion in front of others. This includes a broad range of activities through which people take part in government policy and shape the decisions that affect their lives.

### **Socio-political scenario and the role of Government and NGOs**

Socio-political scenario for leprosy affected people was characterized by several challenges and discrimination in many parts of the world. One of the most significant issues faced by the leper is the deep-rooted social stigma associated with the disease. Leprosy can lead to physical disabilities, which can result in economic hardship as affected individual may face challenges in finding suitable employment opportunities. As a result they are forced to go through begging. Besides it many leprosy affected individuals are forced to live in leprosy colonies or secluded communities, further contributing to their social marginalization.<sup>9</sup> However political support for leprosy related issues may be hindered by a lack of awareness and advocacy efforts, both at the local and global level.

Being a fundamental right, everyone has the rights to contest and participate in political process in a democratic country but there are some states in India like Rajasthan which prohibits leprosy patients from running in local elections and excludes them from employment opportunities and other socio-political benefits.<sup>10</sup> Telengana has three different laws like the Greater Hyderabad Municipal Corporation Act, 1955 which excludes an individual suffering from leprosy from being nominated as a member. Neighboring Andhra Pradesh has also practiced such laws.<sup>11</sup> Exclusion from the political affiliation for a particular group like leprosy affected people leads to cultivate a barrier for them to make their own decisions and share their problems with the authority. This type of socio-political barrier directly attacks the sustainability of this particular community. To eliminate the political discrimination with the leprosy sufferers, there is a need of affirmative action based on right-based approach to spread the awareness at grass root level like Zila Parishad (i.e. District Level), Block Samiti (i.e. Community Level) and Gram Panchayat (i.e. Village Level) and also about their political rights which is given and protected by the Constitution of India.

The role of Government, Non-Governmental Organization and several organizations is crucial in supporting leprosy affected people and addressing their challenges they face. The government and NGOs should work hand in hand to provide comprehensive healthcare, promote political-social awareness, fight stigma and empower leprosy affected individual to lead fulfilling lives



after treatment.<sup>12</sup> By addressing the medical, social, political and economic aspects of the disease, they can contribute to the eventual elimination of leprosy as a public health problem. Both the govt. and NGOs can work together to raise awareness about leprosy, dispel myths and reduce the stigma associated with the disease. Educational programs can also be conducted to promote early detection and timely treatment.<sup>13</sup> Government also must implement inclusive policies to safeguard the rights and dignity of leprosy affected individual. This include protecting them against discrimination and ensuring equal opportunities for education, employment and participation in society.<sup>14</sup> NGOs often play a crucial role in advocating for leprosy affected individual's rights both local and international level. They can raise awareness among policymakers and the general public, influencing policy changes and resource allocation.<sup>15</sup> There are numerous non-government organizations like The Leprosy Mission Trust of India (TLMTI), Sasakawa India Leprosy Foundation (SILF), Association of People Affected by Leprosy (APAL) India, Sara Bangla Kustha Kalyan Samiti, West Bengal., who work in this sector through providing awareness with right-based approach by extending linkages between Self-help Groups and DPOs to develop the different skills and abilities among leprosy sufferers that are mandatory to participate in political process like public speaking, problem solving skills and campaigning. The founder of Sasakawa India Leprosy Foundation, Mr. Yohei Sasakawa made a comment during his visit to leprosy colonies of West Bengal-**"India is a beautiful country, but many parts of it still face the sensitive problems of high discrimination and a major social stigma for the leprosy inflicted people. We aim to provide them a life with dignity, with better education for their children and pension for the elderly and ensure them acceptance into the society. After meeting and understanding them, one major thing I can conclude to is leprosy situation in India needs help, and necessary support to the leprosy affected people and their families should be extended to change the scenario"** (Mediashine, 25<sup>th</sup> September, 2013).SILF dedicated to the task of mainstreaming leprosy affected and cured people through economic and social empowerment. The Leprosy Mission Trust of India (TLMTI) supports leprosy affected individual to gain information, skills and knowledge to enable them to participate in political process.<sup>16</sup> After these affirmative rigorous efforts by different organizations at grass root level in some states like Chhattisgarh, Maharashtra, West Bengal and Uttar Pradesh, over 190 leprosy affected people contested elections to Panchayati Raj Institutions in which 83 won; other 54 leprosy affected people were nominated to various Panchayat sub-committees.<sup>17</sup>

Leprosy patients constantly face various problems. The problems and causes are discussed below-

### **Stain and Stigma:**



Stigma is an attribute that is deeply discrediting... reducing a person from a whole and usual person to a tainted, discounted one.<sup>18</sup>

Leprosy has been associated with deep-rooted social stigma and misconceptions. The stigma surrounding the disease often results in the social isolation of leprosy-affected individuals, limiting their ability to participate fully in political activities. Discrimination, including denial of political rights, remains a significant barrier to their political inclusion in West Bengal.

#### **Lack of Awareness and Education:**

One of the key obstacles to political participation among leprosy-affected people in West Bengal is the lack of awareness and education. Due to limited access to quality education and information, many individuals affected by leprosy are unaware of their political rights and the mechanisms through which they can engage in the political process.

#### **Limited Representation:**

The representation of leprosy-affected individuals in political offices or decision-making bodies is scarce in West Bengal. The lack of representation deprives them of a voice in policy-making processes which directly affects their lives. Without adequate representation, the specific needs and concerns of this marginalized community are often overlooked.

#### **Organizational Efforts:**

Several Non-Governmental Organizations (NGOs) and civil society groups are working to address the issues faced by leprosy-affected individuals in West Bengal. These organizations strive to empower and mobilize the affected community, raise awareness, and advocate for their political rights and inclusion. However, the reach and impact of these efforts are often limited due to resource constraints.

#### **Government Initiatives:**

The Government of West Bengal has taken some initiatives to support leprosy-affected individuals. These include healthcare services, rehabilitation programs, and awareness campaigns. However, political participation is an area that requires further attention and specific policies aimed at ensuring the inclusion of leprosy-affected people in the political sphere.



## **Findings**

Moreover the research analyzes successful initiatives and strategies that have empowered leprosy affected individuals and fostered their political inclusion in different colonies or regions. It showcases case studies of community-led organizations, governmental programs and grassroots movements that have advocated for the rights of those affected by leprosy, challenging norms and amplifying their political representation.

Firstly, the findings of the research will contribute to a deeper understanding of the challenges faced by the lepers in participating political process.

Secondly, the study aims to raise awareness among policymakers, civil society organizations and the general public for promoting a more inclusive and equitable political environment that respect the rights and voices of leprosy affected individuals.

Thirdly, it contributes in the development of an insight into the current level of political participation among leprosy-affected individuals in West Bengal, including their engagement in voting, attending political rallies, and joining political parties.

Fourthly, the study identifies key barriers faced by leprosy-affected individuals in the political participation including stigma, discrimination, lack of access to information, and inadequate representation. It further exhibits before the policy-makers and advocacy groups about the specific challenges faced by these marginalized people.

Last but not the least, the study finds out strategies and interventions to enhance the political inclusion of leprosy-affected individuals, such as awareness campaigns, capacity building, policy advocacy, and collaboration with relevant stakeholders.

## **Conclusion**

Finally, the paper concludes with recommendations for policymakers, practitioners, and other stakeholders for promoting political awareness and participation among the leprosy community. The recommendations of the study include strategies to reduce stigma and discrimination, enhance access to information and resources, promote community empowerment, and strengthen the political voice of the leprosy affected people. The paper also highlights the need for further research and advocate efforts to redress the social and political challenges faced by individuals affected by leprosy and to promote their active participation in the political processes which would democratize their lives. The article highlights



the importance of addressing the political inclusion of leprosy-affected individuals in the politics of West Bengal. The paper emphasizes the need for future research and policy interventions to promote social justice and inclusivity for this vulnerable population. Moreover the study analyzes successful initiatives and strategies that have empowered leprosy affected individuals and fostered their political inclusion in different colonies or regions. It showcases the case studies of community-led organizations, governmental programs and grassroots movements that have advocated for the rights of these people, challenging norms and amplifying their political representation. The findings of the research will contribute to a deeper understanding of the challenges faced by the leprosy community in participating political process. The study aims to raise awareness among policymakers, civil society organizations and the general public, promoting a more inclusive and equitable political environment that respect the rights and voices of leprosy affected individuals.

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