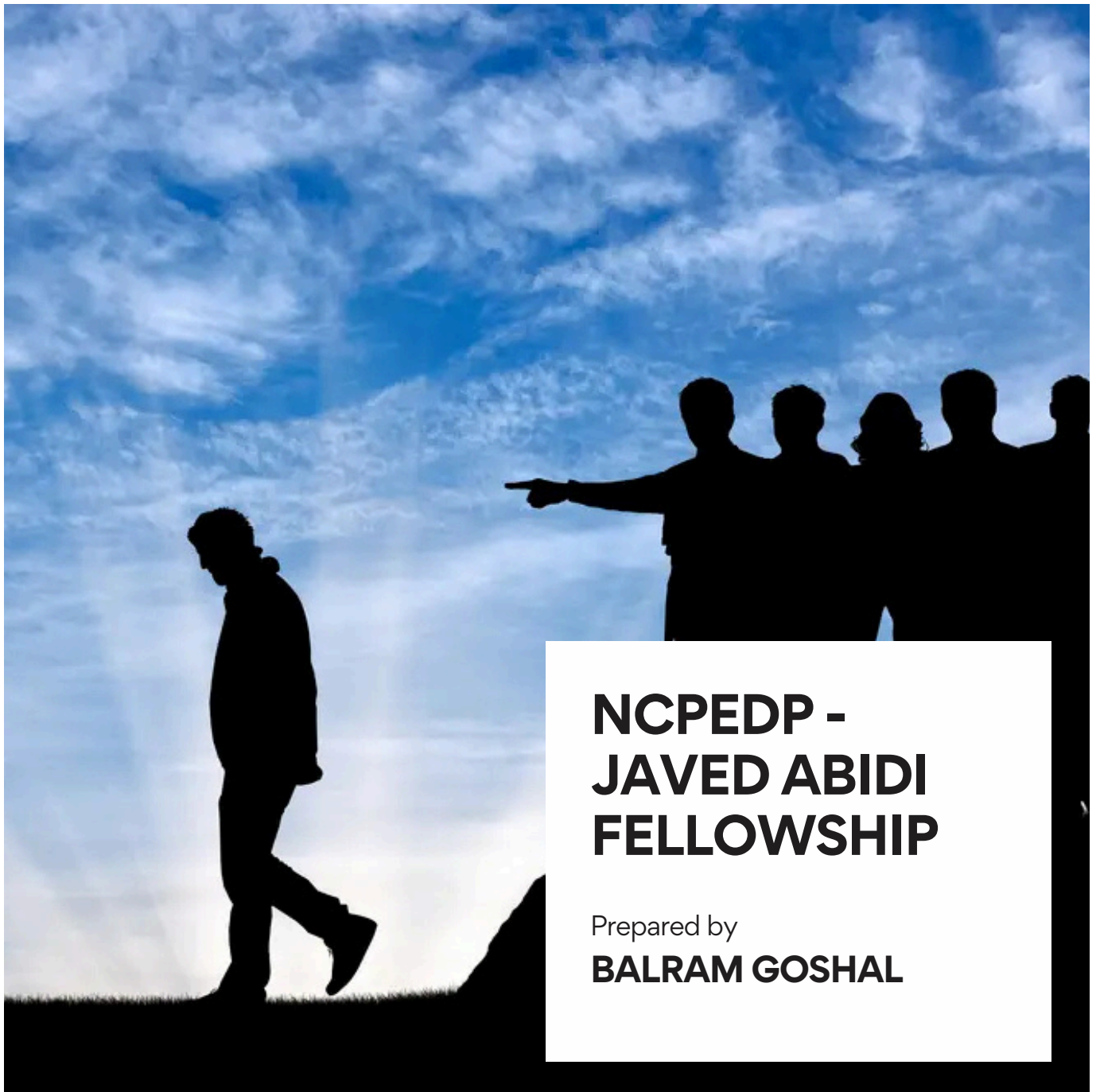




From Seclusion to Inclusion



NCPEDP - JAVED ABIDI FELLOWSHIP

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BACKGROUND

Born in Vrindavan, Mathura, in a leprosy colony, Balram's childhood was shaped by the societal stigma associated with leprosy. Both of his parents were affected by the disease, which forced them to move from their hometown in Bankura, West Bengal, to the seclusion of a leprosy colony. This stigmatization, compounded by economic hardships, meant his parents, like many others in the community, resorted to begging for survival. The misconception that leprosy is highly contagious led to the separation of children like him from their families. From the age of five, Balram was sent to hostels in various cities across India—Lucknow, Gwalior, Shivpuri, Haridwar, Unnao, and back to Vrindavan—to pursue his education. These experiences were often harsh, with strict rules governing interactions between the children and their parents, and at times, even cruel treatment by hostel authorities.

Despite these challenges, Balram persevered in his education. Initially, he dropped out after the 8th grade due to family responsibilities, working as an electrician's helper to support himself. Eventually, he completed the 10th grade and continued his education, earning an ITI Electrician certification and acquiring numerous technical and design skills. However, his career aspirations were shaped by a desire to address the injustices and hardships faced by people affected by leprosy. The memories of his parents' struggles and the systemic exclusion they endured ignited a passion within him to bring about social change.

Choosing his research topic for the NCPEDP Javed Abidi Fellowship on Disability was deeply personal. Having witnessed firsthand the social and economic barriers faced by leprosy-affected individuals, Balram chose to focus on ensuring social security and dignity for these marginalized communities. The fellowship provided an opportunity not only to research these issues but also to advocate for systemic changes in policies and awareness, particularly in Uttar Pradesh, where leprosy-affected communities are often overlooked. The experiences of his parents, who were denied the chance to lead a dignified life due to societal prejudices, served as the driving force behind his research and advocacy work.

PROGRESS OVERVIEW

Half Year 1

- In the initial six months of his fellowship, Balram's primary focus was on understanding the landscape of social security schemes for leprosy-affected individuals. His research
- Began with a literature review on social security and its application to persons affected by leprosy.
- Balram learned to develop problem trees, design studies, and create qualitative and quantitative questionnaires.
- His early efforts also included extensive outreach, sending questionnaires to over 300 individuals in Uttar Pradesh, including leprosy-affected people, NGO representatives, and their families.
- The response rate from these attempts was minimal, which prompted Balram to shift strategies. He started conducting in-person interviews and data collection visits to leprosy colonies and The Leprosy Mission (TLM) centers in places like Ayodhya, Prayagraj, Barabanki, Lucknow, and Mathura
- Over the first six months, he was able to gather data from 200 individuals, enabling him to build a baseline understanding of the social and economic challenges these communities face. He also began analyzing the data to identify key areas where intervention was most needed.

Half year 2

- The second half of Balram's fellowship was focused on advocacy and action. Using the data collected, he worked on creating a media and advocacy plan to raise awareness about the gaps in the social security system for leprosy-affected individuals.
- His work involved engaging with government officials, including the District Leprosy Officer (DLO), State Leprosy Officer (SLO) on 22nd May '24, and local representatives of Ayushman Bharat on 26th September' 24, to address the issues identified in my research.
- Balram also conducted five community meetings on 14th September '24 , 22nd June'24, 26th June '24, 27th June '24, 11th August '24 to directly engage with the affected individuals and ensure their voices were heard.
- On 23rd June '24 he had a follow up meeting with the DLO which culminated in a report on the issues faced by persons with leprosy.
- One of the key areas of his advocacy was addressing the shortcomings in the leprosy pension schemes. Through his efforts, Balram helped six individuals apply for the pension, a significant achievement given the bureaucratic hurdles involved.
- Although he faced challenges in resolving issues related to Ayushman Bharat, Balram's advocacy efforts laid the groundwork for future improvements in access to healthcare for leprosy-affected individuals.

Half Year 3 (May 23- Oct 23)

- Co-authored update on status of Implementation of RpWd Act in Haryana for consultation organized by NCPEDP in Dehradun.
- RTI was again filed with NHRC for, the response firstly received was encoded for disaggregation and it required further clarification on the codes used.
- Reached DGP through email on 22.09.23, for an appointment to meet and request to issue enforceable guidelines for the Chandigarh Police Department, making it mandatory to mention victim's disability in the FIR given that last effort with ministers landed him up with executives who were not the right to make the amendments.
- Did a sensitization session with parents and their children with disability on 05.10.2023 at Government school, Mohali
- Raised it as a suggestion on "Mann ki baat"
- Met Ms. Kanwardeep Kaur, SSP Chandigarh on 05.10.2023 and 20.10.2023 to request her to issue guidelines for mentioning the disability of the aggrieved in the FIR. She was also the first ever official to mention that inclusion of disability column in the FIR on a national level is only possible through appropriate changes in Crime and Criminal Tracking Network & Systems(CCTNS)

Half Year 4 (Nov 23- April 24)

- He was announced as the Purple Ambassador of Cerebral Palsy at the International Purple Fest 2024
- Met State Disability Commissioner Haryana on 21.12. 2023 and requested him to send recommendations to Haryana Police Department for issuance of enforceable guidelines in order to record cases of crimes against persons with disabilities in the State Of Haryana.
- The very next day, i.e on 22.12. 2023 Haryana state commissioner of disability released orders for Haryana Police Department, recommending it to issue enforceable guidelines for recording the crimes against persons with disabilities in the state based on his findings.
- As part of his responsibilities as a Purple Ambassador at the International Purple Fest 2024, he raised the issue of the nationwide scarcity of data on crimes against persons with disabilities during the All State Disability Commissioners Meet. He presented this issue before all the State Commissioners of Persons with Disabilities, as well as the Deputy Chief Commissioner of Persons with Disabilities. Consequently, the Court of the Chief Commissioner for Persons with Disabilities took due cognizance of the matter and issued a notice to the MHA and NCRB for a response on this pertinent issue.

ACHIEVEMENTS

- Successful mobilization of individuals in leprosy-affected communities to access social security benefits. Through direct intervention and advocacy, Balram was able to assist six individuals in applying for the leprosy pension scheme, overcoming bureaucratic hurdles and lack of awareness.
- Balram's research provided valuable data that highlighted the gaps in healthcare and social security for these marginalized groups, which will serve as a foundation for future advocacy efforts.
- His work also involved building a network of government officials and NGOs who can collaborate to improve the social security framework for leprosy-affected individuals.

EXPERIENCE IN THE FELLOWSHIP

The NCPEDP Javed Abidi Fellowship on Disability was a transformative experience that allowed me to develop both personally and professionally. Initially, I struggled with the technical aspects of research, having limited formal education. However, with the support of my mentors, I quickly learned to adapt and apply my technical skills to research and data analysis. The fellowship also gave me the opportunity to engage directly with policymakers and government officials, providing me with invaluable advocacy experience.

One of the most rewarding aspects of the fellowship was the direct impact my work had on the lives of leprosy-affected individuals. The research I conducted not only highlighted critical issues but also provided practical solutions, enabling people to access much-needed social security benefits. The challenges I faced—such as low response rates to questionnaires, limited support from partner institutions, and bureaucratic delays—taught me resilience and the importance of perseverance in social justice work.

The fellowship was not just about research; it was about bridging the gap between policy and people, ensuring that the voices of the marginalized are heard. This experience has reinforced my commitment to working for social change and addressing the systemic issues faced by vulnerable communities.

RESOURCES

Follow Balram's work on their social media

