



**NCPEDP**

JAVED ABIDI FELLOWSHIP

# TRANSFORMATION JOURNEY



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JAVED ABIDI  
FELLOWSHIP**

Prepared by  
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# BACKGROUND

Aarti Batra is a 25 year old woman with an invisible disability, Thalassemia Major. She is from Gurgaon, Haryana. She did her schooling from Sh. S.N. Sidheshwar Public School, a small public school in Haryana. Aarti has had a very close experience with healthcare systems and has always been interested in working towards it. She has had first person experience with existing gaps in health infrastructure and systems.

She completed her graduation and postgraduation in English Literature and is highly interested in analyzing the nitty gritty of literary works written by women. She is someone who is extremely passionate about the feminist movement, human rights, accessibility, and impactful research. She aims to work towards bringing the invisible disability discourse and representation in the mainstream. She has been working in the disability sector for the last two years through the Javed-Abidi Fellowship Program During her Fellowship Programme by NCPEDP. During the program she assessed the accessibility and availability of Public Healthcare for Persons with Disabilities in Gurgaon. She also worked towards identifying gaps and reaching practical solutions with the officials in the last one year.

Aarti is undertaking research on accessible and equitable healthcare services in Gurugram. She has been actively engaging with ASHA and Auxiliary nurse midwife workers. In course of her field engagement, she conducted regular sensitization workshops for them to equip them with understanding of disability. She along with other fellows also undertook a campaign on invisible disabilities. Aarti has co-authored and published a paper in TISS' journal for disability studies. Her publications also include an article on "World Thalassemia Day: An invisible disability that is lacking acceptance" in The Hindu.

Aarti has been recently enrolled in a PhD program at University of Delhi and she will be studying the memoirs of women with invisible illnesses and their potential contribution to the emerging discipline of medical humanities.

# PROGRESS OVERVIEW

## **NOVEMBER 2021 TO APRIL 2022**

Introduction of the Research Intervention:

Despite the prevalence of disabilities and their direct connection with the healthcare sector, there is a significant lack of data on how public healthcare manages disabilities, especially in underprivileged and underdeveloped areas. The research papers "Access to Primary Health Care Among Persons With Disabilities in Rural Areas: A Summary of the Literature" and "Addressing the Health Needs of People with Disabilities in India" highlight global and regional barriers faced by persons with disabilities (PwDs). Our focus is on Gurgaon district, where significant gaps in public healthcare exist, particularly in underprivileged areas.

- A comprehensive review of literature and policies relevant to the area of research was done in order to gain documented knowledge to understand the healthcare issues faced by PwDs.
- Communication was initiated with government officials to seek their support for the intervention project. Support letter/ meetings ANM CMO SDM (minutes of meeting)
- Aarti developed a qualitative questionnaire for interviews to conduct a baseline survey. This created a structured approach for gathering primary data.
- Visits were made to various local locations to conduct interviews with the community members, AASHA workers and medical officials. These visits were crucial for gathering insights into the gaps and challenges in healthcare services for PwDs.
- **A Secondary Study** was conducted, identifying the lack of focused research on the “impact of the healthcare crisis on disabilities”. Aarti found global studies highlighting increased health risks for PwDs, prompting a deeper local assessment.

- **Primary Study:** In-depth interviews revealed a narrative shift between community members and medical officials regarding healthcare challenges. This fieldwork enhanced communication, networking, and documentation skills.

## ***MAY 2022 TO OCTOBER 2022***

- A Baseline Report was prepared detailing the findings from the initial research and fieldwork. Some of the conclusions drawn from the report are: (Baseline: 1 pager and highlights of the report)
- A meeting took place with the Deputy Commissioner, seeking permission for conducting awareness training sessions for Asha workers. The aim of the training sessions was to empower Asha workers with knowledge and skills to better support PwDs.
- Aarti developed a structured reservoir of awareness resources for use in campaigns. This was done to ensure easy access to awareness materials for effective community mobilization.
- A video documentary was developed with the community and Asha workers highlighting healthcare challenges for PwDs. The documentary was used as an advocacy tool to raise awareness and drive change.
- Aarti's social media campaign was planned to highlight findings and promote advocacy efforts. This was done in order to reach a broader audience and build public support for healthcare improvements.

## ***NOVEMBER 2022 TO APRIL 2023***

- The year began with participation as a Purple Ambassador for Thalassemia at the Purple Fest in Goa, an inclusive event that brought together around 1.5 lakh delegates. This role provided a platform to raise awareness about thalassemia and advocate for improved healthcare and support systems. Interaction with various stakeholders, including Disability Commissioners from multiple states, allowed for the presentation of baseline findings on the challenges faced by individuals with blood disorders.

- Additionally, speaking on a panel discussion, findings were presented to key health officials, including the Disability Commissioner of Madhya Pradesh and the Chief Medical Officer of Goa.
- Following the Purple Fest, a training session for community workers associated with ASTHA was conducted, focusing on early intervention and identification of blood disorders. This session aimed to enhance the workers' understanding and ability to identify and respond to such conditions effectively. The training included an impact assessment to measure its effectiveness and was well-received by the 28 participants.
- In parallel, an initiative was launched to develop a formalized early intervention and identification screening tool for community workers and first responders. Secondary research was conducted on existing tools used for screening various disabilities, especially those invisible in nature such as developmental delays, neurodivergence, and intellectual disabilities. The research highlighted the absence of established mechanisms for identifying blood disorders, prompting further investigation and development efforts.
- Interviews with officials from the Rashtriya Bal Swasthya Karyakram (RBSK) were conducted to understand the tools they use to assess various disabilities. Additionally, as a speaker at a state-level meeting on "Defending the Rights of Persons with Disabilities" organized by SLIC, the challenges of invisible disabilities and healthcare access were highlighted, and baseline findings were presented.
- A significant meeting was held with Dr. Satendra Singh, which focused on early intervention and diagnosis of disabilities. Feedback from this meeting suggested conducting a more focused study on existing systems before developing new mechanisms. Participation in the G-20 consultation on Health and Disability also provided a platform to raise concerns about the outdated medical curriculum in relation to disability.

- In May, efforts were concentrated on developing a grant proposal for the Azim Premji Health Research Grant to support initiatives on access to primary healthcare for people with disabilities. Although the proposal was ultimately unsuccessful, it involved comprehensive technical and financial planning. Additionally, preparation and presentation at the North-East Consultation on Disability Rights in Dehradun provided an in-depth analysis of the administrative status of the RPwD Act 2016 in Haryana.
- An article was published in The Hindu on World Thalassaemia Day, highlighting the challenges and needs of individuals with thalassaemia. Participation in the International Conference on Disability and speaking at a panel discussion organized by Sarathie addressed employment challenges faced by people with invisible disabilities.
- The ongoing secondary research on early intervention and diagnosis tools involved contacting various NGOs and organizations to understand their approaches, with initial efforts focusing on developmental delays. Attendance at a capacity-building workshop organized by NCPEDP further enhanced advocacy skills and network-building capabilities. Presentations of baseline findings were made to esteemed guests and board members at UNESCO, and collaboration began for an audiovisual documentary to document case studies more impactfully.

### **MAY 2023 TO OCTOBER 2023**

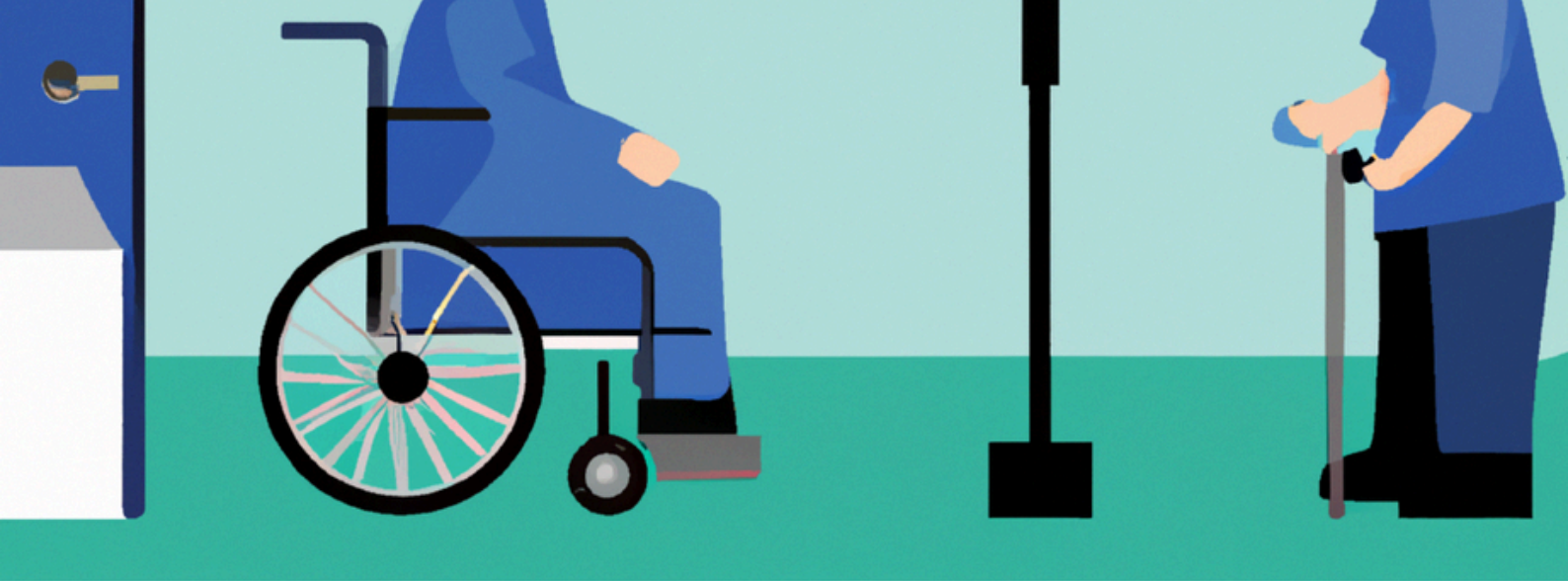
- In the last leg of the fellowship programme Aarti started working on developing campaign and advocacy strategies with the collaboration of other fellows. Aarti in her research findings also concluded that the understanding around disability is very limited even at the elite and high end places. The idea of disability is based on visibility. So, Aarti in collaboration with another fellow Anjali Vyas, developed a social media platform that talked about invisible disabilities through storytelling.

- The fellowship helped her develop leadership competencies to take on this task and lead a campaign successfully. The networks and connections that developed through the fellowship program were a great help in making the campaign a success.
- Aarti also presented her baseline findings to various administrative officials like Mr. Praveen Ambastha (Dy. comm CCPD) and Mr. Guru Pavaskar (Disability State Commissioner, Goa) to propose an intervention programme.
- She has also developed a research proposal that examines the intersection of disability and poverty in India and is in the process of allocating funding to develop a holistic research methodology.



# ACHIEVEMENTS

- Development of research and advocacy skills
- Building connections across the disability community and getting a platform to voice the work.
- Developing an organisation as a founder and building it to work on grassroots. Leveraging all the connections developed during the fellowship program to get collaborations and support.
- My major achievement would be to develop a holistic understanding of disability studies and sectors through the resources provided by the fellowship. The 2 year program equipped me to understand the nuisance of disability research and representation. The fellowship helped me immensely to develop my Phd Research Proposal.
- Developing a leadership competency that enables me to run a small team at our newly registered Organization and also bring in new projects.



# EXPERIENCE IN THE FELLOWSHIP

I have said it time and again that the fellowship has helped me become a different person. I have become more confident and comfortable with myself as I have gained enough knowledge through the program to be sure of my opinions and perspectives. It has made me an empathetic individual who sees the world with a lens where disability is not excluded. Today, my understanding of disability theory, research, and academic interventions are all a result of this program as it gives me a foundational development. I know we all have fellows achieved many accolades being part of the fellowship and for our work but I will always think that the biggest achievement for me in this fellowship will be the person I transformed into.

# RESOURCES

**Follow Aarti's work on their social media**

