

Priya Srivastava: "Courage doesn't always roar; sometimes, it's the quiet voice at the end of the day saying, 'I will try again tomorrow.'"

Background

Priya Srivastava is a lawyer, disability advocate, and NCPEDP Javed Abidi Fellow. She holds a Bachelor of Commerce from Lucknow University and an LL.B. from Shri Jai Narain PG College in Lucknow, and she has also completed the Company Secretaries Foundation level. Her advocacy journey is deeply influenced by her personal experiences, particularly living with spinal muscular atrophy, which has fueled her commitment to advancing disability rights and accessible caregiving support in India.

Due to her condition, Priya was homeschooled until the seventh grade, with invaluable support from her teachers, Arti Ma'am and Rohini Ma'am. Arti Ma'am created a school-like environment at home, teaching each subject in an hour and providing structure through exams and report cards, which kept Priya academically engaged. Rohini Ma'am played a pivotal role by helping her gain admission to a formal school, believing in her potential and encouraging her to pursue her dreams. Despite achieving a 9 CGPA, Priya faced rejections from schools for 11th grade due to concerns about her disability. These challenges only strengthened her resolve to advocate for those whose disabilities limit both their physical movement and access to education and community.

Today, Priya's work emphasizes that caregiving is an essential component of accessibility—not just about physical adjustments like ramps, but also about having someone available to assist with daily needs. Without caregiving support, tasks such as transferring from bed to wheelchair or from wheelchair to car become significant barriers. She has led webinars on topics such as ableism, caregiving policy, and awareness of Spinal Muscular Atrophy. Additionally, Priya has engaged with policymakers, including members of the Legislative Council and the Deputy Chief Minister of Uttar Pradesh, to advocate for a national caregiving policy.

Half Year 1 (May' 2023 - Oct'2023)

- At the inception of her research process, Priya conducted an in-depth [literature review](#) and developed a [problem tree](#) to map and address core caregiving challenges.
- She successfully gathered [109 responses](#) via a [Google form](#) to assess the caregiving needs of individuals with disabilities.
- Thereafter, she undertook the significant task of compiling over [30 detailed case studies](#) that highlight the unique experiences and challenges faced in the realm of caregiving. Each case

study serves as a comprehensive narrative, providing insights into the personal stories of individuals and families navigating the complexities of disability and care.

- She held productive meetings with key officials, including the [Disability Empowerment Officer](#), [Regional Director](#), and [Disability Commissioner](#), to discuss the proposed caregiving policy.
- She actively engaged with [parents of individuals with intellectual disabilities](#) at various events, including the [National Trust's Rojgar Mela](#), to gain firsthand insights into their unique caregiving needs.
- Visited [SPARC India](#), [PGI Hospital on Down Syndrome Day](#), the [Composite Regional Centre](#), and [Chetna School](#) for mentally disabled children to gather additional case studies and network with caregivers and families.
- Priya has been actively involved in [media advocacy](#), using various platforms to raise awareness about the challenges faced by individuals with disabilities and the crucial role of caregiving. Her approach focuses on leveraging the power of storytelling and factual reporting to engage the public, influence policy discussions, and promote a more inclusive society. Through interviews, articles, and social media campaigns, Priya effectively communicates the pressing issues surrounding disability rights and caregiving.

Half Year 2 (Nov'2023 - April' 2023)

- Priya has taken significant strides toward improving caregiving for individuals with disabilities. She developed an [advisory form](#) designed to gather specific caregiving needs and activity descriptions directly from disabled individuals. This initiative aims to create an inclusive caregiver needs list, ensuring that the voices of those directly impacted are heard and considered.
- Currently, she is preparing a comprehensive [compendium](#) that addresses a range of caregiving needs. This resource will cover essential topics such as necessary equipment, daily roles of caregivers, and travel assistance, providing a holistic view of what is required for effective support.
- In addition to these practical resources, Priya is drafting articles that compile relevant laws and provisions from the [Rights of Persons with Disabilities \(RPWD\) Act, 2016](#), the Indian Constitution, and other supportive legislation. This documentation aims to bolster advocacy efforts for better caregiving policies, grounding her work in a solid legal framework
- Priya has created an [overview of disabilities](#) as defined by the RPWD Act. This overview identifies essential equipment and support roles that caregivers need to fulfill their

responsibilities effectively, ensuring that caregivers are well-equipped to meet the unique needs of each individual they support.

- Presented a letter of appeal for caregiving support policy to the [Deputy Chief Minister](#).
- Priya submitted an [appeal letter](#), endorsement letter, and request letter to a [Member of the Legislative Council](#), advocating for policy considerations in caregiving.
- She is continuously recording individual [case studies](#) that highlight daily caregiving roles and the specific challenges faced by disabled individuals in travel and public life. By capturing these real-life experiences, Priya aims to shed light on the barriers that exist and advocate for meaningful changes in policies and practices. Her work not only emphasizes the importance of personalized caregiving but also strives to foster a more supportive environment for disabled individuals in society.
- Priya secured numerous [endorsements](#) for an appeal letter advocating for structured caregiving support.
- Priya has taken a proactive role in [drafting policies](#) that emphasize the importance of caregiving in India, recognizing that effective caregiving is essential for enhancing the quality of life for individuals with disabilities.
- Priya completed the [baseline report](#), conducting analysis and chapterization, and presented findings on project progress, followed by a strategic review meeting. Following were some of the recommendations conceptualized:

a) Establishment of a Dedicated Sub-Ministry: The government should create a dedicated sub-ministry focused on caregiving to oversee and coordinate policies, programs, and services for individuals with disabilities and their caregivers.

b) Corporate Social Responsibility Engagement: Private players should allocate CSR funds towards initiatives supporting caregivers, including training programs, financial assistance, and awareness campaigns.

Here is the link to the entire baseline report:
https://docs.google.com/document/d/1jbfnokQAETdIj88Q50VjPlmrOmopVsqq/edit?usp=drive_link&ouid=103198202964358884441&rtpof=true&sd=true

Major Achievements

- Proliferated awareness through several [webinars](#) on key topics such as:

- a) [Spinal Muscular Atrophy Awareness Month: Emphasizing the importance of caregivers](#)
- b) [Ableism on Caregiving Needs: Addressing the need to shut down ableism in caregiving.](#)
- c) [Caregiving Baseline and Rough Policy Presentation: Presenting a foundational caregiving policy](#)

Experience in the Fellowship

My fellowship journey focused on advocating for individuals with disabilities and their caregivers. I conducted a literature review, gathered insights from 109 individuals through a Google form, and compiled over 30 case studies to highlight caregiving needs. I created an advisory form for disabled voices in policy and prepared a compendium on essential caregiving needs. Presenting an appeal letter to the Deputy Chief Minister and securing endorsements aimed to integrate caregiving into mainstream discussions, underscoring the need for structured support to enhance the quality of life for disabled individuals. At the beginning, I had the invaluable guidance of Ujjwal Ma'am and Sumit Sir, who both helped me clarify my goals and provided me with the practical steps needed to move forward. A particularly impactful presence in my fellowship was Swati Ma'am, my mentor, who supported me in building a network within the disabled community. Her connections and guidance were instrumental in helping me gather case studies and compile the evidence I needed for my research. Sumit Sir, however, was the true pillar of my fellowship. He served as my first mentor, offering support in multiple ways—from guidance in documentation to helping me overcome issues that surfaced frequently throughout the fellowship. His advice was steady and practical, keeping me grounded and focused during stressful times, especially when faced with the demands of media outreach or data collection. Sumit Sir frequently shared resources and study links to deepen my knowledge, addressing every question I brought to him with patience and insight. His mentorship provided the backbone I needed to persevere and grow.

Additionally, I was fortunate to receive valuable lessons from Armaan Sir, especially during fellowship workshops where we had the chance to interact. His wisdom extended beyond the technicalities of disability advocacy, often addressing life goals and personal growth within and outside the disability sector. Engaging with key officials, such as the Disability Empowerment Officer, Regional Director, and Disability Commissioner, allowed me to discuss the proposed caregiving policy in depth. I also attended multiple events—including the National Trust's Rojgar Mela and visits to SPARC India, PGI Hospital on Down Syndrome Day, the Composite Regional Centre, and Chetna School—where I

interacted with parents, caregivers, and individuals with disabilities. These experiences enriched my understanding and provided me with additional case studies to support my advocacy.

I used various media platforms to raise awareness about the crucial role of caregiving, focusing on storytelling and evidence-based reporting. Through interviews, articles, and social media, I communicated the pressing issues surrounding caregiving and disability rights, aiming to build a more inclusive society.

In the fellowship's second phase, I took major strides in advancing caregiving support for disabled individuals. I developed an advisory form to gather specific caregiving needs and activity descriptions directly from individuals with disabilities. I presented a letter of appeal for caregiving support policy to the Deputy Chief Minister and submitted additional appeal and endorsement letters to a Member of the Legislative Council. I continued to record case studies that highlight the daily caregiving roles and challenges faced by disabled individuals in travel and public life. Through these narratives, I aim to shed light on existing barriers and advocate for policy reforms.