

**“JUST BECAUSE IT IS NOT
VISIBLE, DOES NOT MEAN
IT DOES NOT EXIST”**



**NCPEDP -
JAVED ABIDI
FELLOWSHIP**

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BACKGROUND

It was 2014, when during her final year of Chemical Engineering (from College of Engineering & Technology Akola) she faced loss of vision, with other symptoms such as disorientation, extreme & unusual fatigue, numbness which were intermittent episodes and led her to be diagnosed as a person with Multiple Sclerosis. “I would feel fatigued and sometimes faint amidst the rumour that I am pregnant amongst friends making the progression of my condition even more traumatic. I lost a month’s college and then reached out to my Class Teacher who, being concerned about the attendance, asked me to reach the Head of Department. Soon, I ended up in hospital when my visiting friends told me about me being blacklisted for taking exams given my poor attendance. Instead of focusing on my recovery, my family had to invest energy on meeting my HOD who was not even bothered to ask us to sit upon entering his room. The aura resonated towards him not believing and instead telling "don't tell me stories; you look absolutely fine to me”. The continuous pleading to the college faculty may have led the administration to inform her to be seated for exam a day before it began like a king on one fine day, taking out the garland from their neck and bestowing grace upon a labour, never known; never acknowledged. She had received placement, earlier that year from a Polymer manufacturing company, based in Anand Gujarat and was supposed to confirm her acceptance by June 2014. Her parents were not supportive of the idea given episodes of recent health conditions and she then started to make her ends meet by providing home tuition. She started to look for opportunities based in Nagpur, nearest (80 kilometres away) to her home in Bhandara. She found an opportunity from Supreme BituChem India, Pvt. Ltd. for the position of Product Development Executive and Sales coordinator. “ After 4 months of things going well and settling down well for me I was also assigned to a role that was a good progression, but soon I had an episode of vision loss which led to absenteeism making my employer unhappy on one end, and my doctor extremely concerned on the other”.

She chose to listen to her Neurologist who had advised on taking things slow in life and taking up a livelihood that does not lead to variable routine and undue pressure. She got back to her home and continued tutoring students, took the test of IELTS (International English Language Testing System) and turned into a certified trainer in 2018. She started working as a trainer in Pune for a well known Academy. “This time I was quite upfront about Multiple Sclerosis and my limitations during recruitment and I found the founder to be a well read lawyer who understands disability and started working with the organisation. After three months, he(founder) started to negotiate with me to take additional sessions for PTE(Pearson test of English) & work in shifts everyday for he found me doing well and my concerns as mere psychological fears, which soon led to another relapse because of travelling twice a day, working in shifts. My roommate informed him as well which he did not believe until he saw me lying on the hospital bed. My legs were shaking; I slurred while speaking and certainly not in a state to train. Yet, when I went back to demand my rightfully earned remuneration which was overdue, he ended up deducting my salary & for the absence; when it was him who led me to it”. But, the experience made them take a call on her shifts and she asked to take one shift of training and help them document a book for which they did not even agree to acknowledge the contribution or pay a royalty. This soon made her realise the mindset of exploitation and decided to leave the job, taking trauma ahead further to fight for a simple experience certificate. She then has been working as a freelance Trainer on her own terms and making ends meet; using the right means.

This was a period when her connection with MSSSI developed and helped her gain much needed support and have space to discuss discriminating experiences which demand protection of rights. She also started to cross paths with other organisations and individuals working on disability inclusion like being part of Voluntary National Review consultation organised by NCPEDP. The experiences introduced her to a new space invigorating new ideas for herself to own it and lead it. She thus started her journey in the fellowship and chose to work with employers so they do not question what is not visible.

PROGRESS OVERVIEW

NOVEMBER 2021 TO APRIL 2022

- Her inclination since beginning was to look at the array of issues faced by persons with invisible disabilities like Multiple Sclerosis. She found that there are several rights and needs which are [being advocated by MSSl](#) (Multiple Sclerosis Society of India). She found that narratives are being generated by the society towards several thematic areas of intervention but a focused approach on employment.
- She herself had faced challenges in gaining meaningful employability so she started to understand the gaps leading to employment of people with MS. She realised that largely it was around skill gaps or reasonable accommodations in place for the skilled workforce to have inclusive norms for people with MS. This led her to work on employment of persons with MS.
- She began to understand preferences of people with MS through MSSl Pune Chapter's database in terms of employment. She reached out to society's working with blood disorders like Thalassemia but could not receive similar data points and she focused her [data collection](#) through MSSl's chapters and network of other fellows to reach to other people with invisible disabilities, CRC(Composite Regional Centre for Skill development, Rehabilitation & Empowerment of persons with disabilities) Nagpur, [DDRC](#) (District disability Rehabilitation Centre) Nagpur.
- She also started to use her active involvement on platforms like [LinkedIn](#) for extending outreach.
- She started to have conversations with job enablers for persons with disabilities like [Enable India](#), Sarthak Educational Trust, V-shesh, [Youth4Jobs](#) to confirm if lack of skills and sensitization of employers are an actual issue for people with disabilities.

- She realised that her network could be capitalised in terms of sensitising employers, job enablers, DPOs and NGOs facilitating employment. While she was reaching out to people with MS at MSSSI Pune she made 68 calls and found that 65% of people had the education which could support an employment opportunity which could ensure retention and promotion, 48% were unemployed and 18% of people had left the job because of insensitive employers which made her inclined to look at sensitization of employers. It was also learning to find that 17% of the employed people were not open to their employers to reveal MS for fear of losing out the opportunity & other 17% of the employed do not have supportive employers, for them to seek reasonable accommodation.
- The insights helped her develop a study design to help her understand the status of employment of persons with invisible disabilities better, and the challenges faced towards / during gainful employment. The study incorporated mixed methodology and she used her developing network of connections to snowball the responses.
- She started to also use social media handles to make her network updated and aware of lived experiences of people with invisible disabilities to not only grow the network but leverage the same for future advocacy.

MAY 2022 TO OCTOBER 2022

- The data insights from baseline study and case studies developed helped her regularise her series of social media activities under “MSunderstand” initiative in collaboration with NGO Trinayani which helped her snowball relationship with British Telecom through V-shesh, which started her journey of sensitising employers inclined to hire people with disabilities.

- On the occasion of [World MS day](#) observed on 30th May, British Telecom celebrated it through an [online sensitization session](#) for [over 60 employees](#) where V-shesh had recommended Anjali to take the session. She used the opportunity to sensitise employers on concepts, facts and misconceptions around MS through stories, activities, facts and figures.
- She continued her collaborative relationship leading to [another online session with EY\(Ernst & Young\)](#) in June with over 80 Participants leading to a similar sensitization workshop.
- It was followed by [RISE EduTech, Pune](#) conducting a similar session.
- Prior to this very session she had advocated with Orchvate, a job enabler to specify in their job descriptions the roles which are open for persons with disabilities for, not having a mention of the same leads to discouraging approach towards applying for the most post which they not only started to specify the same but also started to work with Anjali on sensitising employers (like had she requested) starting with RISE EduTech, Pune.
- She did [another workshop with Atkins](#) in September with 156 Participants and continued with such a series of sessions that year.
- She also started to analyse the data received, and document the draft baseline study which could be refined further through different perspectives later.
- Few of the major findings were: -
 - 1.Of the 42.2% employed respondents, more than 60% work in the private sector
 - 2.50% of respondents cited challenges associated with their invisible disabilities.
 - 3.81.3% were unaware of reasonable accommodation
 - 4.All the telephonic interviews that were cited in the Baseline report, indicated lack of employer support.

Click here to access the complete report.

She also collaborated with 3 other fellows to start joint Invisible campaign called [BELIEVE IN THE INVISIBLE](#) in the month of October 2022 to spread further awareness to a wider audience on the issue.

NOVEMBER 2022 TO APRIL 2023

- The campaign on invisible disabilities helped her also network with heads of Diversity and Inclusion department like Director, NASSCOM, DEI, Ms. Leenika Khattar and understand through the horse's mouth on corporates lagging behind in terms of adopting equal opportunity space and there is a much needed requirement to bring forth such transformation and also look at best practises like was elaborated by Mr. P. Rajasekharan (Founder, V-shesh) during the discussion.
- The thoughtful engagement helped her align her direction of advocacy towards continuing discussion with employers and their DEI experts, government bodies related to the skilling sector given the lack of skills amongst PwDs.
- She also continued sharing job roles available for persons with disabilities and motivating them to apply for it even if the roles did not especially mention it as an equal opportunity.
- She reached out to Ms. Divya Sharma, Consultant, Central Project monitoring Unit (CPMU), DePwD while networking with all the ambassadors of Purple Fest. She shared her findings of the baseline and explored the possible policy transformations which can be attained through support of DePwD. It was during such multiple conversations on guiding her direction of advocacy she helped her look at measures on sensitization done by the skilling department towards reasonable accommodation for persons with Multiple Sclerosis. And, eventually she was connected to Ms. Maitrayee, Consultant from Skilling department of CPMU at DEPWD of PwDs to look at one stop centre helping trainees to seek support post placement for facilitative and conducive migration. She brought her global perspective of good practices in place in developed countries to gradually look into creating a one stop support centre like PM Daksh Platform, introduced later for supporting meaningful employment of PwDs with access to information towards not only opportunities but also their rights.

- She continued sensitisation of corporates like [Extentia](#), by networking with all the CSR funding bodies investing on Multiple Sclerosis. It was attended by over 30 participants on 8th Feb 2023 which was an in-person session in Pune.
- She also used to regularly equip herself with events on Inclusion and participate in such events on a monthly basis. She attended an important event of Randstad India where they released a [report](#) on Inclusion highlighting [facts](#) and figures related to invisible disabilities. The learning helped her in refining her baseline study further.
- She continued her research as well to develop narratives of people with blood disorders taking strategic help of ASHA workers but it did not lead to a snowballing effect for invasion of privacy was a concern for workers.

MAY 2023 TO OCTOBER 2023

- She continued her regular connection with executives of DePwD to work in collaboration towards ideating further the creation of a one stop facilitative centre for employment of PwDs with a select group of people of diverse backgrounds.
- The engagement furthered into her supporting the development of a handbook by [NCVET \(National Council of Vocational Education and Training\)](#) to improvise the training ecosystem for PwDs. She had created a dedicated section on working with trainees with Multiple Sclerosis with additional recommendations on accessibility provisions for other disabilities at the training centres.
- The effort to sensitise organisations continued with Deloitte and [CRC Nagpur](#) on 19th October 2023 and 27th October respectively.

- Her continuous networking with stakeholders led her to get in touch with Ms. Sonica Aron, Founder, Marching Sheep to support their intervention on mapping persons with Multiple Sclerosis to match their skills for relevant roles for gainful employment. She later also delivered a session on Creative inclusive workplaces for persons with disabilities for senior leaders from different companies as a part of [Marching Sheep's DEI certification course](#) in collaboration with FICCI .

ACHIEVEMENTS

- Played a pivotal role in ensuring increased accessibility for Persons with Disabilities (PWDs) in her hometown by successfully advocating for the installation of a ramp at the Village Council.
- Helped a PwMS secure a remote job by sharing relevant job ads for PWDs and engaging with Sarthak Educational Trust.
- Invited for panel discussions at [Flex](#) and [KPMG](#) in November and December 2022 due to the success of her Invisible Disabilities campaign.
- Selected as the Ambassador for MS by the State Commission for Person with Disabilities, Goa, at Purple Fest 2023 in acknowledgment of her advocacy efforts on invisible disabilities.
- Following the success of "Believe in the Invisible", she also earned the privilege to co-organize a Disability Conference focused on Invisible Disabilities and established an exclusive space in the Experience Zone dedicated to Invisible Disabilities at the International Purple Fest 2024.

Please click [Impact and Policy Change](#) for details



EXPERIENCE IN THE FELLOWSHIP

The NCPEDP-Javed Abidi fellowship program was an experience that truly enriched my life. While I came in brimming with excitement to delve into the world of Disability Advocacy, there was also a healthy dose of nervousness. After 5 years spent comfortably training students, becoming a Fellow meant stepping into a completely new space – one where I was the learner, not the teacher.

It was a refreshing change. Immersing myself in Disability Advocacy through workshops and discussions opened doors to new knowledge, especially the importance of networking. A health challenge threw me off course, but the incredible support from NCPEDP and co-fellows helped me navigate it all. Looking back, the fellowship wasn't just about knowledge, it was right kind of learning about inclusion, humility, and self-discipline – a truly rewarding journey.

RESOURCES

Follow Anjali's work on their social media

