

NCPEDP - Javed Abidi Fellowship on Disability

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Baseline Report

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Employment for Persons with Multiple Sclerosis

(an Invisible Disability)

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1 Acknowledgements

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I am grateful to the Multiple Sclerosis Society of India, Pune chapter, who provided me with critical information on the persons with MS registered with them. This further helped me understand the status of employment and reasons for unemployment among persons with MS.

I wish to express my gratitude to my mentor Renuka Malaker who helped me steer through the process of the survey, right from the primary survey.

Lastly, it is important to mention that without the support of several disability organisations and my co-fellows, it would not have been possible to reach out to persons with disabilities for my baseline survey.

Anjali Vyas

NCPEDP – Javed Abidi fellow on Disability

A person with Multiple Sclerosis

2 Abbreviations

tention Deficit/Hyperactivity Disorder Imposite Regional Centre for Skill Development, Rehabilitation & Empowerment of ersons with Disabilities Imposite Regional Centre for Skill Development, Rehabilitation & Empowerment of ersons with Disabilities Imposite Regional Centre for Skill Development, Rehabilitation & Empowerment of Empowerment of Scheme Imposite Regional Centre for Skill Development, Rehabilitation & Empowerment of Empowerment of Scheme Imposite Regional Centre for Skill Development, Rehabilitation & Empowerment of Empowerment of Persons with Disabilities Imposite Regional Centre for Skill Development, Rehabilitation & Empowerment of Empowerment of Persons with Disabilities Imposite Regional Centre for Skill Development, Rehabilitation & Empowerment of Persons with Disabilities Imposite Regional Centre for Skill Development, Rehabilitation & Empowerment of Persons with Disabilities Imposite Regional Centre for Skill Development, Rehabilitation & Empowerment of Persons with Disabilities Imposite Regional Centre for Skill Development, Rehabilitation & Empowerment of Persons with Disabilities Imposite Regional Centre for Skill Development, Rehabilitation & Empowerment of Persons with Disabilities Imposite Regional Centre for Skill Development, Rehabilitation & Empowerment of Persons with Disabilities Imposite Regional Centre for Skill Development, Rehabilitation & Empowerment of Persons with Disabilitation & Empower
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3 Executive Summary

Invisible disabilities, as the term suggests, are those disabilities that are not visible or are hidden from the human eye. The most common invisible disabilities known are autism spectrum disorder, depression and learning disabilities such as ADHD and dyslexia. However, chronic illnesses such as neurological conditions and blood disorders which affect the quality of life of an individual are also invisible in nature. While individuals with visible disabilities have long grappled with employment challenges, it is essential to recognise that PwIVD confront similar hurdles.

The landscape of disability rights in India has been undergoing a significant transformation, reflecting a growing awareness of the need for inclusivity and equal opportunities for persons with disability, right from the establishment of the RCI in 1952 to promote and regulate rehabilitation efforts for PwD, to the enactment of the RPWD Act in 2016, protecting the rights of PwD. While significant progress has been made, challenges persist, including the need for greater awareness, better enforcement of disability laws and enhanced access to employment.

With less than 25 per cent of workspaces in India having adequate facilities to accommodate people with disabilities, workplace inclusivity remains a critical concern, especially for those with invisible disability.

Disability inclusion policies play a crucial role in ensuring equal opportunities and support for persons with invisible disabilities. However, the onus also lies on the employees with invisible disabilities to promote a culture of acceptance and reduce the stigma. The employers and the government should actively collaborate with disability organisations and advocacy groups to gain insights, resources, and guidance on supporting employees with invisible disabilities.

Notably, India has witnessed a scarcity of comprehensive studies concerning the employment landscape for individuals with invisible disabilities, specifically those encompassed by the Rights of Persons with Disabilities Act 2016, such as Multiple Sclerosis, Haemophilia, Thalassemia, and Sickle Cell Disease. Consequently, this baseline study was undertaken to identify existing gaps, observe employment-related concerns of PwIVD, and formulate strategies for their alleviation.

"Many times, invisible disabilities can impair the ability to work under normal conditions or participate in social activities at work. People with invisible disabilities can have dramatic limitations with typical work activities, and it can be difficult for co-workers to acknowledge, recognise and understand the disability."

Linda Fisk, CEO & Founder, LeadHERship Global

4 Introduction

4.1 Background

The Invisible Disability Association defines invisible disability to referring symptoms such as debilitating pain, fatigue, dizziness, cognitive dysfunctions, brain injuries, learning differences and mental health disorders, as well as hearing and vision impairments.

Adopting the principals of <u>UNCRPD</u>, <u>The Rights of Persons with Disabilities Act</u>, <u>2016</u> defines a person with disability as "a person with long-term physical, mental, intellectual or sensory impairment which, in interaction with barriers, hinders his full and effective participation in society equally with others". Barring the physical disabilities, other categories of disabilities such as Multiple Sclerosis and blood disorders are not prominent because of the absence of understanding of their nature and symptoms surrounding them.

For a long time, invisible disabilities have not been well understood as they have invisible symptoms such as chronic pain, fatigue and dizziness, which can be also observed in people with Multiple Sclerosis and blood disorders. These disabilities are mostly diagnosed at a young age, which impacts not only education but also the employment of PwIVD. Despite India being one of the first countries to ratify the UN Convention of Rights of Persons with Disabilities, it was only in the year 2016 that the chronic neurological conditions Multiple Sclerosis and Parkinson's Disease, and blood disorders Haemophilia, Thalassemia and Sickle Cell Disease were added and recognised as disabilities in the Rights of Persons with Disabilities Act.

For many persons with disabilities, their environment plays an essential role. Like any other disability, invisible disability can also be an acquired one and does not necessarily have to be hereditary or from birth. The invisible nature of this disability makes them more vulnerable to their environment and disproportionately affected. The degree is dependent on the environment they operate in, especially for working professionals living with invisible disability.

According to a 2017 study conducted by the Centre for Talent Innovation in the US, almost 30 per cent of the white-collar workforce lives with invisible disabilities. Unfortunately, India lacks sufficient data on this, so we do not even know the extent of the problem here.

A study by diversity and inclusion consultancy, INvolve in the UK has found that two in three employees with invisible disabilities receive no support from their employer.¹

Research shows that 88 per cent of employees with invisible disabilities choose not to disclose it at work to avoid stigma and discrimination. Those who do open up about long-term invisible disabilities are often <u>socially isolated</u>, resulting in lower morale and reduced productivity.

Employment for persons with Multiple Sclerosis (an Invisible Disability)

¹ Personnel Today; May 5, 2023 – "People with invisible disabilities left to fend for themselves at work, finds study" - https://www.personneltoday.com/hr/invisible-disabilities-at-work-involve-research/

A primary survey conducted in 2019 with 450 PwMS by the MSSI, Delhi Chapter (see Annexure) revealed that around 30-35 per cent of the PwMS who wanted to work were unemployed and 15-20 per cent faced job loss. This was owing to the social stigma and the fear of job loss due to the invisibility of the disorder.

In India, even after being added to the RPWD Act 2016, the assessment guidelines for chronic neurological conditions and blood disorders do not take invisible symptoms into account, which hinders identification and inclusion of PwIVD. As per the assessment guidelines of the RPWD Act, chronic neurological conditions can be assessed only as a percentage of Permanent Physical Impairment/Locomotor Disability. This may not be applicable to all PwIVD but makes it difficult for the majority of PwIVD to avail of a disability certificate/UDID for them to be counted. With no disability certificate or UDID, it becomes more challenging for them to benefit from government policies.²

The 4 per cent employment quota under Section 21 of the RPWD Act does not include these invisible disabilities. Chapter 6 of the RPWD Act 2016 dictates 1 per cent reservation each for people with low vision and blindness, deaf and hard of hearing, locomotor disability, autism, intellectual disability, specific learning disability and mental illness. There is no reservation for people living with MS as well as for people with blood disorders recognised under the RPWD Act, for which associations for people suffering from MS, Parkinson's Disease, Thalassemia, Haemophilia and Sickle Cell Disease wrote to the Prime Minister in July 2018, demanding reservation in the employment quota.³

In the private sector, the scenario is no different. An article from People Matters from 2020 states that "if we look at the best practices, the focus across organisations has largely been on visual and hearing disabilities. Awareness of disabilities such as Multiple Sclerosis and Parkinson's Disease is still very low in the corporate sector and their inclusion therefore is low."⁴

For people with blood disorders, the workplace may not be as conducive. As per the <u>Labour Law firm</u>, New York on Disability discrimination faced by people with blood disorders, "Once an offer is made, and an employer is made aware of the presence of an employee's blood disorder, the employer may be leery of continuing illness or believe the employee to be high risk. These conjectures may lead the employer to discriminatory conduct, including changes in responsibilities, demotion, outright dismissal, failure to promote, or the creation of a hostile work environment to force an employee out."

² The Pioneer; Oct 3 2020 – "RPWD Act: People with Multiple Sclerosis feel left out"https://www.dailvpioneer.com/2020/india/rPwD-act--people-with-multiple-sclerosis-feel-left-out.html

³ The Indian Express, Aug 13, 2018 – "Five groups for differently-abled write to PM Narendra Modi, demand job quota"https://indianexpress.com/article/india/five-groups-for-differently-abled-write-to-pm-narendra-modi-demand-iob-quota-5303580/

⁴ People Matters, Aug 29, 2021- "Changing landscape for PwD in Corporate India"https://www.peoplematters.in/article/diversity/changing-landscape-for-PwD-in-corporate-india- 30653

The Global MS Employment Report, 2016 shows that many people with MS are leaving employment earlier than necessary. 62 per cent of people with MS who were not in employment said fatigue the most common invisible symptom of MS - prevented them from staying in work, far less than the 85 per cent reported in 2010. It was also revealed that effective changes and adaptations in the working environment such as flexible working hours and places to rest during work breaks could keep more people with MS at work.⁵

It also cannot be denied that there is a lack of skills in people with disabilities, especially those living in rural areas. Additionally, the lack of awareness of their rights and limited number of rehabilitation centres such as the CRCs deprive most of the PwD of the skill development training and employment opportunities. Hence, its crucial to have effective and timely implementation of policies and adequate budgetary allocation to ensure that no one is left behind.

4.2 Objectives of the study

To understand the gap between the situation of employment and awareness on invisible disabilities (MS and blood disorders Haemophilia, Thalassemia and Sickle Cell Disease) in India and the necessary intervention, a baseline study was conducted. Additionally, it was also important to assess the information on:

- 1. Challenges faced by persons with invisible disabilities (MS and blood disorders)
- 2. Status of employment of persons with invisible disabilities and support from their employers
- 3. Level of awareness of reasonable accommodation and equal opportunity policy among persons with disabilities
- 4. Data on the disability certificates/UDID issued to persons with MS and blood disorders

4.3 Process of the study

Following the objectives of the study and the need for necessary intervention, the primary and secondary research were carried out as mentioned below. Desk research was done to set the parameters for the baseline survey. The primary study employed both, quantitative and qualitative analysis, which were conducted online.

Secondary Study: Desk Research

- 1. Global MS Employment Report, 2016 from MS International Federation
- 2. Embracing all Abilities, An Equity, Diversity & Inclusion Study by Randstad India
- 3. Information through RTI from NSDC on skilled PwIVD

Primary Study

- 1. Quantitative Analysis: A baseline survey on the employment status of PwIVD
- 2. Qualitative Analysis: Telephonic interviews of PwMS at MSSI

A detailed structure and information of the two studies are given in the following sections.

⁵ MS International Federation, April 6, 2018 – "Employment and MS" - https://www.msif.org/about-us/who-we-are-and-what-we-do/advocacy/employment-and-ms/

5 Methodology

5.1 Secondary Study: Desk Research

The secondary study was done to identify the gaps in employment for persons with invisible disabilities. The desk research involved secondary data from the Global MS Employment Report 2016, which was available and accessible online, and the use of different advocacy tools such as the RTI.

- 1. The information gathered through the Global MS Employment Report by the MS International Federation demonstrated the reasons for unemployment among persons with MS from 93 countries, India being one of them. It led to a careful reconsideration of the inclusion and status of employment of 12,233 PwMS and the rationale thereof. Most of the respondents were youth, with Relapsing Remitting MS, a common form of invisible MS.
- 2. For statistics regarding PwIVD enrolled for upskilling and employment, the information from the NSDC was gathered through RTI.
- 3. Through an RTI, information from the DEPWD was collected to seek the national data of persons with invisible disabilities; MS and blood disorders.
- 4. Additional secondary data was sought through an online workshop organised by NILERD in February 2022 to gather information on the number of UDID cards issued to PwIVD from 2018 to February 2022.

5.2 Primary Study

Baseline Survey, Google Forms

Although the desk research and RTIs helped to understand the national status of skill development and employment of PwIVD, a thorough survey was a vital tool to collect primary data for identifying the gaps in employment.

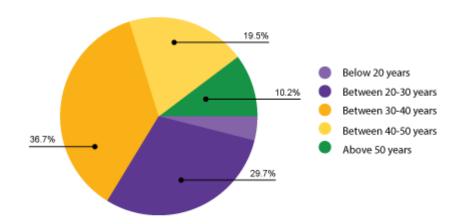
Hence, a baseline survey through Google Forms was conducted to study the status of employment and employers' support of PwIVD in India. The survey also ascertained the awareness of the Reasonable Accommodation & Equal Opportunity policy among PwD.

The survey was bilingual, in English and Hindi, and was carried out between 16 February 2022 and 20 March 2022. The survey was promoted online via WhatsApp groups and LinkedIn, and through emails to the organisations that work for invisible disabilities: MSSI, PDMDS, HFI, National Thalassemia Welfare Society and Thalassemics India.

Sampling methods

Although the desk research and RTIs helped to understand the national status of skill development and employment of PwIVD, a thorough survey was a vital tool to collect primary data for identifying the gaps in employment.

- Data Analysis from MSSI Pune: MSSI Pune's database of 144 registered PwMS in December 2021 was collected in an Excel sheet to analyse their employment status. About 90 PwMS were contacted telephonically. The balance 54 members had not disclosed their contact details and could not be reached. This exercise also provided information on the number of PwMS holding a Disability Certificate or UDID.
- Unstructured Interviews: Simple random sampling was deployed to conduct telephonic interviews with 10 PwMS from different parts of the country. The interviews aided the qualitative analysis of the survey to record the complexities in employment because of the invisibility of MS. Upon prior permission, the interviewees were selected through personal references and were registered members of MSSI. The participants were aged between 20–40 years, six of them being women.

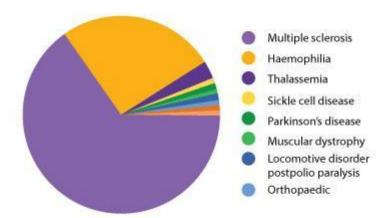


Survey Results

The survey was carried out across India with 128 respondents who were based in 17 states. Most of the respondents were from Karnataka and Tamil Nadu, followed by Maharashtra. 36.7 per cent were between 30-40 years of age, while 29 per cent were in the 20-30 age group.

However, most of these respondents were diagnosed with disabilities when less than 20 years old. The survey had 52 female respondents and 76 male respondents.

Nature and type of Disability



Of 128 respondents, 57 per cent had an invisible disability of some form. The majority had Multiple Sclerosis. 30 per cent lived with a blood disorder, of which 28 per cent reported living with Haemophilia.

The other important information derived from the survey was that 53.9 per cent of the respondents hold a UDID, while 10 per cent are awaiting one. 35.9 per cent confirmed not having a disability certificate or a UDID.

Number of respondents with UDID	69	
Number of respondents awaiting UDID	13] Th
Number of respondents without UDID	46	

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finding underscores the need for streamlined and accessible processes for individuals with disabilities to obtain the necessary documentation, which is essential for accessing rights, entitlements, and support services. Addressing these disparities in documentation is crucial for ensuring equal opportunities and inclusivity for all persons with disabilities.

In contrast, among the 90 PwMS registered at MSSI Pune, only 17 possessed a UDID. This discrepancy arose because many were unaware of UDID, and several did not exhibit visible symptoms that would make them eligible for disability assessment.

The Unique Disability ID (UDID) project⁶ implemented under the SIPDA aims to issue a unique identification number to each person with a disability, enabling authorities to formulate targeted policies and programs. The UDID card is linked to several government welfare schemes and entitlements to promote accessibility and inclusion.

Despite the SIPDA's positive impact, its budget has dwindled in recent years, dropping from INR 315 crore in FY 2019–20 to INR 150 crore in FY 2023–24.7 The budget estimates for the SIPDA

⁶ UDID Project under SIPDA - https://disabilityaffairs.gov.in/content/page/unique-disability-id.php

⁷ Times of India, April 2023 - No Budget for PwD in India

in recent years have shown a fluctuating pattern, translating into a decline in revised estimates reaching -51 per cent in 2020-21 and -29 per cent in 2021-22, compared to the initial budget estimates. The actual utilisation of the funds remained low at 41 per cent in 2020-21 and 51 per cent in 2021-22, indicating non-utilisation of over half the allocated funds. The significant unspent funds can be attributed to the insufficient number of proposals for its sub-schemes from states and union territories in comparison to other schemes that have significant implications for various initiatives, including enhancing skill development for employment, supporting the Accessible India campaign, promoting awareness and publicity, advancing research on disability-related technology, facilitating UDID generation and sensitising key government functionaries.

The secondary data collected through an online workshop organised by NILERD also shed light on the low number of UDID cards issued to PwIVD since the RPWD Act came into force. Of the 60.31 lakh UDID cards issued to PwD since 2018:

- 84,004 were persons with Multiple Sclerosis (0.14 per cent)
- 372,019 were persons with Thalassemia (0.62 per cent)
- 360,018 were persons with Haemophilia (0.6 per cent)
- 54,002 were persons with Sickle Cell Disease (0.09 per cent)

The physical progress of the UDID registration/cards is presented in the table below

	2018	2019	2020	Total
UDID registrations/ cards generated	15,06,703	22,98,249	17,76,054	60,31,419 (as of 24.02.2022)

The information from the DEPWD through an RTI showed similar statistics of persons with MS and blood disorders, who were issued the disability certificate in the state of Maharashtra.

Category	Number of certificates issued
Multiple Sclerosis	486
Haemophilia	932
Thalassemia	1629
Sickle Cell Disease	1820

The

survey

and the UDID data shed light on the low outreach and the lack of assessment of invisible symptoms of the disabilities, which also pose a challenge for a PwMS to get a disability certificate.

In a telephonic interview with a 40-year-old woman with MS from Madhya Pradesh, the struggle to get a UDID came to light.

Sheela (name changed) has been living with Multiple Sclerosis since 2013. Diagnosed with MS at the age of 30, Sheela has a PhD in Biotechnology. She started experiencing symptoms at the age of 28, while pregnant. Although delivering the baby was not a challenge, it triggered the symptoms of MS, resulting in relapses soon after.

Recalling an incident of severe MS relapse, Sheela states, "There was a time when I was trying to tie my daughter's shoelace but could not do it despite several attempts. I was devastated and cried the whole day as I feared getting disabled and asked myself whether I would be a good mother to my only child."

Sheela started working as a professor in the Government College as an ad hoc. She would conduct six lectures a day. With invisible symptoms such as bladder incontinence and fatigue, it was getting difficult for her to work. The college toilets were inaccessible. Fearing job loss, Sheela did not disclose her disability to the HOD. Eventually, the HOD started pressuring her to assist him in his research work for free, which forced her to quit the job. After learning about the RPWD Act in 2018, she applied for a UDID. Rejected by the assessment panel twice because of her invisible symptoms, Sheela wrote to the MSJE. She finally received her UDID in February 2022, with 50 per cent disability.

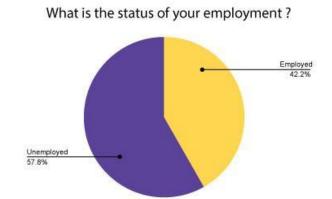
She says, "The RPWD Act is useless for PwMS as it does not consider invisible symptoms during the assessment and many of the government policies have completely neglected MS." Even with the UDID, Sheela cannot apply for a government job, as MS is not part of the 4 per cent employment quota.

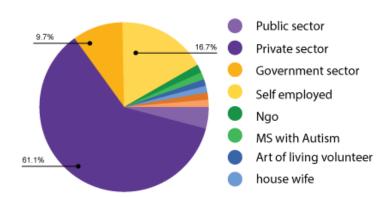
As per the target set under New India @75, 55 lakh UDID cards were to be generated by the Department of Empowerment of Persons with Disabilities by 31 March 2021. 55.80 lakh UDID cards were generated; according to the 28th Report of the Standing Committee on Social Justice & Empowerment (2021-22)⁸.

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^{8 17&}lt;sup>th</sup> Lok Sabha – Standing Committee on Social Justice & Empowerment (2021-22): https://loksabhadocs.nic.in/lsscommittee/Social per cent20Justice per cent20& per cent20Empowerment/17 Social Justice And Empowerment 28.pdf

1.3 Status and Nature of Employment





The key section of the baseline survey concerning the employment status of persons with disabilities indicated that 57.8 per cent of the respondents were unemployed. Of the 42.2 per cent employed respondents, over 60 per cent work in the private sector while 16.7 per cent were self-employed. These findings were similar to the case of PwMS at MSSI Pune.

The survey also highlighted that many respondents did not disclose their disability to their employer due to a lack of general awareness of their disability or a fear of job loss.

Research by the diversity and inclusion consultancy Involve⁹ found that 37 per cent of employees with invisible disabilities had not disclosed their disability at work for fear of discrimination and half felt that it was not worth dealing with the process of gaining support.

Based on telephonic interviews and data analysis conducted at MSSI Pune, it was evident that the concern about losing corporate insurance is a significant factor for the non-disclosure of MS to employers.

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⁹ People with invisible disabilities left to fend for themselves at work (personneltoday.com)

32-year-old Meeta (name changed), who was diagnosed with MS when she was 26, shared her experience of employment at an esteemed organisation. An MBA by qualification, Meeta is presently living with secondary progressive MS. She pursued her graduation in Electronics & Telecommunication Engineering and started working for an esteemed organisation in Mumbai. Dissatisfied with her salary, Meeta decided to pursue a Masters in Business Administration. Soon after she completed her MBA, she started experiencing numbness in her hands and had trouble writing. In 2016, as she turned 26, she was diagnosed with Remitting Relapsing Multiple Sclerosis.

Narrating her plight, Meeta says, "After my diagnosis, due to MS, I experienced brain fog, which affected my cognition. I lost my confidence and was scared to disclose it to my employer. But when it was not getting any better, I shared it with my employer."

She was asked to resign and her corporate insurance coverage was discontinued. For the next two years, Meeta struggled to find a good job while also taking care of her health. In 2018, she was hired by an inclusive organisation in a different city, though this time she chose not to disclose her condition due to fear of job loss and loss of corporate insurance.

A year later, when Meeta got married, her MS progressed and she had trouble commuting to work every day. Due to COVID restrictions, she has been working from home since 2020. A few months ago, on learning about the disability certificate and UDID, she applied for them, As she awaits her UDID, she has decided to disclose MS to her employer and ask for reasonable accommodation. Meeta is confident that her experience with the current organisation will not be as unpleasant, as she works in a team which needs to have a person with a disability (PWD) according to the company's policies.

While concluding, she suggests, "Every organisation must be aware of invisible disabilities such as MS and have a helpdesk for PwD, for such people to feel confident about disclosing their disability and feel belonged. Also, invisible disabilities such as MS must not be excluded from corporate insurance, else, the purpose of inclusion is lost."

As per Randstad India, a prominent HR services organisation's study, 67 per cent of respondents from Indian public sector companies and 55 per cent from Indian private sector companies mentioned that inclusion is present, but not mandated in their goals. This highlights a substantial gap in promoting an inclusive work environment.

5.4 Workplace Challenges

Out of the 128 respondents, 15 received employer support through reasonable accommodation, while 53 faced challenges due to their invisible disabilities. Invisible symptoms such as fatigue, weakness and long working hours were the most reported factors that affect the work of PwHp and PwMS. Some respondents mentioned that the absence of employer support, and workplace adaptations such as restroom facilities, add to their employment challenges.

"I need to travel and visit places and find it difficult to carry factors with me every time," said a respondent with Haemophilia, while sharing workplace challenges, in the survey.

Another PwHp in the survey stated, "Whenever I have internal bleeding, they (employers) do not understand what this is and how to solve it. I am careful about my health but they do not care for me. They forget that I have an invisible disorder."

"The company does not allow me to take time off when I am not feeling well due to Haemophilia," wrote another respondent in the survey.

The survey also captured responses from people with MS who were in employment, who described fatigue, bladder issues, tingling and numbness as the most disabling factors, with little awareness of MS amongst employers, preventing them from working effectively.

Many with invisible disabilities were facing daily struggles in their job roles. The study revealed that 37 per cent of employees with invisible disabilities chose not to disclose their disabilities at work due to concerns about potential discrimination. Additionally, half of them believed that the process of seeking support was not worth the effort. 24 per cent said they were unable to cope with their workload, and 28 per cent said their disability contributed to an inability to concentrate at work.

The Global MS Employment Report by MSIF also suggests major reasons for attrition to be the realm of reasonable accommodation, such as lack of time off needed, unpredictable workload & lack of employer/colleague support. The key findings from the survey revealed that 43 per cent of people with MS who were not in employment had stopped working within three years of diagnosis.

A similar experience was shared in an MS awareness campaign <u>MSunderstand</u> conducted by NGO Trinayani in May 2022. Shweta, a young PwMS diagnosed with MS in her early twenties from a small village near Pune said, "I had to quit my job 2-3 times as I have speech issues because of MS, for which I was always mocked at my workplace".

An unpredictable workload and the lack of employer support were the topmost factors that prevented PwMS from staying in employment. This also holds in the case of persons with blood disorders, as observed in the instance below.

Aarti Batra, a 24-year-old individual from Gurgaon, is a vibrant professional in the disability and research sector and a person with a blood disorder, thalassemia, a disability recognised in the RPWD Act 2016. She holds a Master's degree in English Literature and is actively engaged in research while working towards her Ph.D. Despite her academic achievements and determination, Aarti faces formidable obstacles in her pursuit of a fulfilling career due to her thalassemia, a chronic blood disorder that necessitates bi-monthly transfusions.

Aarti's academic journey, though successful, has had a setback. While she qualified for the UGC-NET in the PwD category, her attempt to secure a position in the ad hoc panel faced limitations. Being required to register in the unreserved category created an unequal playing field, forcing her to grapple with a substantial score gap and placing her at a disadvantage in her pursuit of a job.

Aarti ventured into the private sector, but her experience there was fraught with adversity. The lack of acknowledgment of thalassemia as a disability translated into a lack of reasonable accommodation. Despite existing guidelines advocating extra leave days for individuals like her, Aarti found herself in an organisation that refused to provide this crucial support. She says, "I had to leave my job because I needed leave to take care of my health, which the organisation refused. I cannot get another job because the moment I disclosed my disability, the employer asked me questions as to how I would manage in a competitive workplace and tried to end the conversation."

Aarti encountered difficulties when seeking new job opportunities in the government sector too. The absence of reservations in the 4 per cent employment quota for individuals with thalassemia posed a significant hurdle. The common assumption that Aarti could apply in the unreserved category due to her seemingly 'meritorious' status neglected the fact that merit often hides the advantage some people have in the system. She mentions, "People with disabilities including invisible disabilities need affirmative action such as reservations for them to have a real chance. I have regular medical interventions, complications, health diagnoses, medicinal side effects, and chronic fatigue that often make me compromise with my studies. This is why it gets difficult to get government opportunities." Presently, Aarti yearns for a full-time job that aligns with her skills and passions without compromising her health.

She recently shared her experience on <u>Twitter</u>, recounting her lost opportunity due to the omission of blood disorders from the 4 per cent employment quota. She writes: "Came across an Asst. prof. opportunity at JNU (CES) for PwD. I am PwD as per RPwD act 2016 and I have all the req. and desirable qualifications. Still I can't apply because GOI refuses to include blood

5.5 Knowledge of RPwD act 2016

The RPWD Act, 2016 aims to promote the inclusion and empowerment of PwD in all aspects of life, including employment. These are covered under the following sections:

Section 20 - Non-Discrimination in Employment: Section 20 prohibits discrimination against PwD in matters related to employment. It ensures that no employer can discriminate against a person with a disability in the recruitment, job training, promotion, or any other aspect of employment based on their disability.

Section 23 - Affirmative Action by Private Establishments: This section encourages private establishments with 20 or more employees to take affirmative action in favour of PwD by providing facilities and opportunities to promote their employment.

Section 24 - Non-Discrimination in Promotion: Section 24 ensures that PwD are not discriminated against in matters of career advancement, including promotions.

Section 25 - Right to Equal Opportunities in Employment: Section 25 lays down the right of PwD to equal opportunities in employment and outlines that they should be provided with an enabling work environment to perform their duties.

Section 26 - Skill Development and Training: This section emphasises the need for skill development and training programs for PwD to enhance their employability and enable them to secure suitable employment.

Section 27 mandates that the government and private establishments shall provide reasonable accommodation and accessibility features in the workplace to ensure that PwD can effectively perform their job duties.

Randstad India's exclusive study on Equity, Diversity & Inclusion (ED&I) called 'Embracing All Abilities' revealed that not even one in four Indian workspaces are equipped to accommodate PwD. Additionally, the survey showed that:

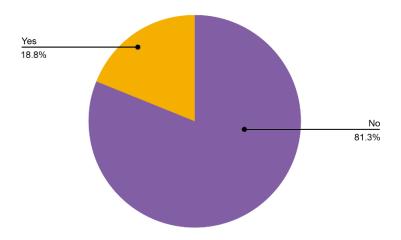
- 65 per cent of the organisations have policies to include PwD, of which 19.5 per cent are Indian private sector companies while only 4.5 per cent of public sector companies have inclusive policies.
- 67 per cent of the Indian public sector companies and 55 per cent of private sector companies said that inclusion is present, but not mandated in their goals.
- Less than 25 per cent of workspaces in the country provide PWD accommodation necessities such as accessible toilets, technical aids, and appropriate seating arrangements.

Effective disability inclusion policies in the workplace indeed have far-reaching benefits but, since not all disabilities are visible, employees have the choice to disclose them. This

presents a dilemma for those with hidden disabilities to decide whether to disclose or not, as it can only then encourage them to request for accommodations.

Hence, the baseline survey employed two questions to gain insights to the awareness of the Equal Opportunity Policy and Provision of Reasonable Accommodation among PwD.

Are you aware of Reasonable Accommodation mentioned in Chapter 4, Section 20 of the RPWD Act 2016?



With only 27.3 per cent of respondents aware of the Equal Opportunity Policy and only 18.8 per cent aware of the provision of reasonable accommodation, it is evident that there is a need to raise the awareness amongst PwD of their rights and provisions through the <u>SIPDA</u>.

The Rights of Persons with Disabilities Act establishes the obligation to reserve specific job positions for individuals with disabilities in both, the public and private sectors. To comply with these legal obligations, employers frequently seek candidates who possess the requisite skills and qualifications. While there is provision for jobs for PwD under the 4 per cent employment quota, there is no reservation for invisible disabilities such as MS and blood disorders.

Hence, skill development plays a pivotal role in facilitating employment opportunities for PwIVD to work in the private sector. The DEPWD under the Ministry of Social Justice and Empowerment implements several schemes for entrepreneurship and skill development of PwD, such as the NHFDC, DDRS, skill training through the National Institutes, and the National Action Plan for Skill Development of Persons with Disabilities under the SIPDA¹⁰.

The National Action Plan (NAP) was launched in collaboration with the Ministry of Skill Development and Entrepreneurship in 2015 to provide skill training to PwD¹¹. The NSDC is the implementing agency for the NAP. In the financial year 2019-20, NAP did not meet its target,

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¹⁰ Skill Development for PwD by Department of Empowerment of Persons with Disabilities National Portal of India

¹¹ National Action Plan for Skill Training of Persons with Disabilities Launched (pib.gov.in)

serving only 1,434 beneficiaries of the planned 20,000. However, by 2021, the Department had trained about 150,000 *divyangjans*. In a bid to bolster the employment prospects of PwD through the NAP, the DEPWD recommended the integration of the 'Incentive to Employers in the Private Sector' scheme into the NAP. This was discontinued in 2022 in the fifth meeting of the Central Advisory Board on Disability¹², because despite the scheme's increased publicity through the SIPDA, its accomplishments were not as substantial.

An analysis of expenditure related to Awareness Generation & Publicity (AGP) under the SIPDA from 2019 to 2022 sheds light on the efforts made towards sensitising key personnel in the Central and State Governments, local bodies, and other service providers. In 2019, AGP's total expenditure was Rs 2.12 crore, surpassing the allocated budget of Rs 2 crore, to hold 16 physical events as part of the awareness campaign. However, over the subsequent years, there was a noticeable decrease in the number of physical events and the expenditure. In 2022, the number of physical events dropped to a mere six, and the expenditure amounted to Rs 2.11 crore. This was below the allocated budget of Rs 2.8 crore for that year.¹³

This trend implies that it has a substantial influence on the development of awareness campaigns and sensitisation programs for a range of stakeholders including private-sector employers, as it affects the efforts to establish barrier-free environments for PwD and the incentivisation of private-sector employers to hire PwD.

However, the competitive environment in the private sector can often pose challenges for PwD, especially those with invisible disabilities, in terms of traditional employment opportunities. In such a competitive landscape, several factors can limit their access to suitable jobs and lead them to consider self-employment as a viable alternative.

The NHFDC provides financial assistance for skill development and self-employment ventures for PwD through several schemes and initiatives¹⁴.

Furthermore, the lack of opportunities in the private sector, exacerbated by prejudice, limited accessibility, and fierce competition, often compels individuals with MS to turn to self-employment.

During an interview with Ishita (name changed), she expressed her interest in starting her business due to progressive symptoms of MS. Ishita was 23 years old, when she was diagnosed with MS in 2020. After a year, she was diagnosed with Primary Progressive Multiple Sclerosis, which restricted her mobility and worsened the symptoms, both visible and invisible.

Ishita comes from a developed city in south India, which has developed infrastructure, access to healthcare and transport, and better job opportunities. She recalls having the symptoms of MS since 2019 but not taking them seriously. She lives with her retired parents, and a twin sister who is an MBA in Marketing. Holding a Bachelor's degree in IT, Ishita worked with Amazon before she was diagnosed with MS. As her MS progressed, she continued to work despite being asked to quit. In October 2021, she quit her job as her symptoms worsened.

She was treated for her symptoms. As the treatment became unaffordable, Ishita started

Employed for part time jobs. During this time, her fatigue levels rose. This was mistaken for laziness by her parents. Talking about fatigue, Ishita says, "Let alone the sensitisation of society to MS, even my parents are not aware of MS. My relatives do not understand or know

This alternative empowers them to create accommodating work environments and pursue their entrepreneurial goals, which was observed in the following case of PwMS

Another case describing the struggle of living with MS is of Priya (name changed), a 40-year-old woman from the southern part of the country who lives with Secondary Progressive Multiple Sclerosis with a 76 per cent visible disability.

With an educational background in Electronics, she worked for an MNC for four years. As her symptoms progressed, she had to quit her job due to a lack of employer support. After a year, when she learnt about the Equal Opportunity Policy, she approached her employer but did not receive any response. Her husband, a Civil Engineer, was the sole breadwinner of the family of two. They struggled to make both ends meet.

As Priya's condition deteriorated, her husband could not leave her unattended, and they decided to run a food truck. Once, when Priya's husband was out at the food truck, Priya fell from her wheelchair. Narrating the incident, she said, "I was trying to help myself by grabbing something on the opposite side when I fell and felt a terrible pain in my arms. I cried loudly for help but nobody in the neighbourhood responded. For 2-3 hours, I lay on the floor until my husband returned and lifted me." It was a traumatic experience for both. Her husband decided to discontinue running the food truck.

In 2019, the Smart City Project announced in the state gave them new hope. The project dictated under Public Convenience & Amenities that a dedicated piece of land for open plazas would be provided, of which 1 per cent would be allotted to women with a disability. After working relentlessly for several months, the 1 per cent quota for women with a disability was repealed and Priya's husband had to run from pillar to post to fight for their rights. They also filed a case in the High Court and undertook many trips to the Disability Commissioner's Office. This put a huge financial burden on them, but soon, they managed to procure the piece of land in the open plaza for a monthly rent of Rs 21,000. Her husband's friend and business partner now, not only supported the business but also took care of operations at their new food joint inaugurated in May 2022.

Priya concluded, "It took us three years to get justice and what is rightfully ours, despite knowing our rights. I was the only woman with a disability and eligible for the Smart City project quota but was completely ignored. I wish to upskill myself and find a work-from-home opportunity to support my husband."

Priya can apply for loan schemes under the NHFDC through her UDID and help her husband expand their food business. She can also participate in inclusive job/employment fairs for PwD.

The Deen Dayal Upadhyaya Grameen Kaushalya Yojana (DDU-GKY)¹⁵ under the Ministry of Rural Development in India is aimed at providing skill training and employment opportunities

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¹⁵ DDU-GKY - https://www.myscheme.gov.in/schemes/ddugku

to rural youth. Initially, the DDU-GKY did not have skilling of PwD as one of its primary mandates. However, this changed significantly after a <u>crucial notification in 2017</u>.

In 2015, the SCPwD set a goal of training 4 million PwD by 2022. Simultaneously, the Ministry of Skill Development and the Department of Empowerment of Persons with Disabilities aimed to train 2.5 million PwD in the same year. However, with only 165,552 individuals trained as of September 2023, less than 5 per cent of the original target has been met¹⁶. This reveals the substantial gap between the intended objectives and the actual outcomes in terms of skill development and training for PwD in India.

Binding together secondary and primary surveys, and the qualitative survey, it was found that 81.3 per cent of the respondents were unaware of reasonable accommodation. This restricts the utilisation of recruitment and the probability of retention and promotion. The probability is high for such incidences and experiences as the lack of awareness about reasonable accommodation is substantial. This implies that the difficulties faced in traditional employment settings are compelling a significant portion of skilled PwMS to pursue self-employment as a more viable option and is leading a third of the skilled PwMS to opt for self-employment as was also found in the response to the RTI made by NSDC under PMKVY 2.0 and PMKVY 3.0.

Disaggregated data on the number of PwMS and PwBD trained, certified, placed, self-employed, wage-employed and in apprenticeship under PMKVY 2.0 and PMKVY 3.0, till January 2022.

Type of Disability	Trained/ Oriented	Certified	Reported Placed	Self-Emplo yed	Wage-Empl oyed	Apprenticeship
Haemophilia	7	5	2	0	1	1
Multiple Sclerosis	22	15	9	3	6	0
Sickle Cell Disease	2	1	0	0	0	0
Thalassemia	2	0	0	0	0	0

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¹⁶ Live Count, SCPWD - Home | The Skill Council for Persons with Disability (scpwd.in)

6 Limitations of the Study

The study was conducted to understand the challenges in the employment of PwIVD, the level of awareness of the RPWD Act amongst the PwIVD and necessary interventions in this regard. The limitations of the study are:

- 1. The low number of respondents with blood disorders.
- 2. Most of the PwMS were not comfortable with video interviews, hence all interviews had to be conducted telephonically.
- 3. As the organisations that work for PwBD and the PDMDS were not able to provide the data on the status of employment of their members, this potentially useful information could not be used for comparison.

7 Conclusion and Recommendations

The baseline study highlights the employment challenges faced by PwIVD. It emphasises the low awareness of invisible disabilities and the lack of knowledge of their rights among PwD. Self-employment emerges as a preferred option due to limited employer support and accommodation.

To address these issues, the adoption and implementation of the Equal Opportunity Policy and increased awareness of invisible disabilities are imperative. The Equal Opportunity Policy should explicitly urge non-discrimination against individuals with visible or invisible disabilities and provide resources through Employee Resource Groups for PwIVD, including accommodation, training and career development.

An induction manual must include information on disclosure, accommodation and essential resources relevant to employees with invisible disabilities. Regular sensitisation training is essential to foster an inclusive work environment. The policy should be periodically reviewed for effectiveness and relevance.

In the light of the finding of low awareness amongst persons with disabilities about their rights, the execution of the SIPDA under the RPWD Act is the need of the hour. Through the SIPDA, various awareness programs, campaigns and workshops are organised to spread information about disability employment rights, reasonable accommodations, and best practices for promoting inclusivity in workplaces. Significant awareness-building efforts are required at the grassroot level. This requires consistent budget allocation with enhanced utilisation for promotion, with effective monitoring of collaboration with government agencies, disability support groups and NGOs.

Moreover, information about the SIPDA and related services must be accessible to all and must follow accessible formats and effective channels to disseminate information. It is equally

imperative to ensure that the Annual Budget reports and related documents must be accessible to PwD.

To Leave No One Behind, it is crucial to revise the assessment criteria, incorporating invisible symptoms for disability certification to individuals with invisible disabilities, MS and blood disorders in the RPWD Act. An inclusive assessment and certification will not only offer recognition of the invisible disabilities and reduce stigma, but also allow the individuals to access necessary accommodation, whether in the workplace, educational institutions or public spaces.

ILO Convention No. 159, also known as the Vocational Rehabilitation and Employment (Disabled Persons) Convention, was adopted by the International Labour Organisation in 1983. While India has not ratified this specific convention, it is still important to understand its provisions when formulating policies and practices related to disability employment.

A dedicated online platform similar to JAN (Job Accommodation Network) in the United States with free, expert and confidential guidance, and training on disability employment must be set up in India. The platform could serve as a comprehensive resource centre and a support network for individuals with disabilities seeking employment opportunities and reasonable accommodations in the workplace. It will also play a pivotal role in bridging the gap between employers and employees with disabilities by educating employers about the diverse needs of PwD.

8 Best Practices

Some of the notable projects/initiatives that focus on addressing invisible disabilities in workplaces are:

Lemon Tree Hotels: This prominent hospitality chain in India has made commendable efforts to ensure the inclusion of persons with disabilities in their operations. Recognised for its commitment to providing accessible and welcoming environments to all guests and employees, Lemon Tree is also known for hiring people with invisible disabilities; especially the deaf and and those with intellectual disability.

The Valuable 500: A global movement that encourages influential companies to prioritise disability inclusion in their business agenda. The initiative aims to ensure that disability - including invisible disabilities - is recognised as a leadership and business priority.

Minds@Work: A UK-based initiative that focuses on mental health in the workplace, including invisible disabilities such as depression, anxiety and bipolar disorder. The project offers resources, training and consultancy services to promote mental health awareness and support employees with invisible disabilities.

Disability:IN: A global nonprofit organisation that works with businesses to advance disability inclusion and equality. Their initiatives and programs focus on all types of disabilities, including invisible disabilities, to create more inclusive workplaces and foster disability-owned businesses.

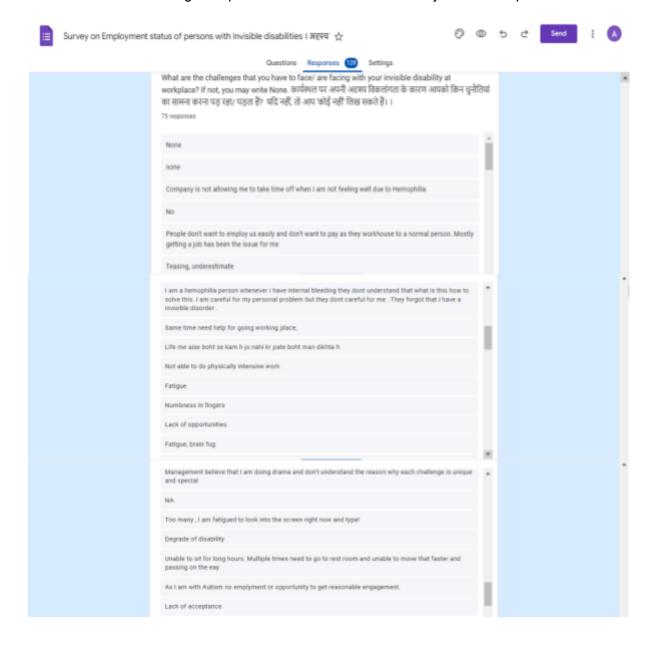
The Hidden Disabilities Sunflower: An international campaign that raises awareness of hidden disabilities, including conditions such as autism, chronic pain and cognitive impairments. The project promotes the use of a sunflower symbol to indicate that an individual may have an invisible disability, helping to foster understanding and support in various settings, including workplaces.

9 References

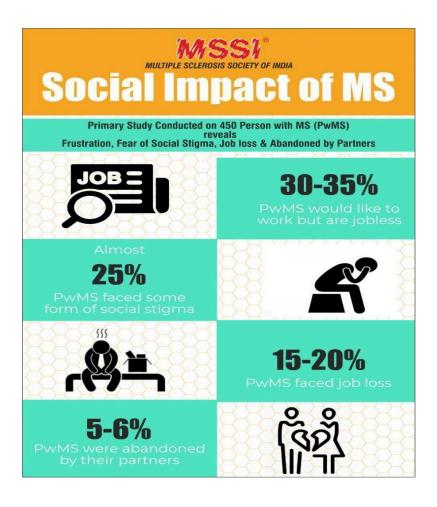
- 1. Harvard Business Repview, April 2023: How to Make Workplaces More Inclusive For People with Invisible Disabilities
- 2. Ministry of Social Justice & Empowerment, DEPWD, December 2021: 29th Report by Standing Committee on Social Justice & Empowerment (2021-22)
- 3. Department of Empowerment of Persons with Disabilities: Union Budget 2021-22 and 2022-23
- 4. Ministry of Social Justice & Empowerment, Department of Empowerment of Persons with Disabilities: Annual Report 2022-23
- 5. Incentive Scheme for Providing Employment to PWD in the Private Sector
- 6. Compendium of Schemes for the Welfare of Persons with Disability, 2018
- 7. Draft of National Policy for PwD, 2021 by DEPWD, MSJE
- 8. Allaya Cooks-Campbell, Sep 2021: Disability Inclusion in the Workplace: The What, Why and How
- 9. Laura Sherbin & Julia Taylor Kennedy with Pooja Jain- Link & Kennedy Ihezie, Centre for Talent Innovation: Disability & Inclusion US Findings TWO SEPARATE REFERENCES?
- 10. Peg Rosen, understood: Understanding Invisible Disabilities at the Workplace

10 Annexures

- 1. Consent form for interviewees for the use of case studies in the Baseline Survey
- 2. Responses from the Baseline Survey Question no. 18: What are the challenges that you have to face/are facing as a person with an invisible disability at the workplace?



3. Primary Survey conducted by MSSI Delhi on the social impact of MS



4. The baseline Survey was conducted through Google Forms, a screenshot of which is shared below

Survey on Employment status of persons with Invisible disabilities । अदृश्य विकलांगता से प्रभावित व्यक्तियों के रोजगार की स्थिति पर सर्वेक्षण

* R	Required
1.	Email *
	Personal Information । व्यक्तिगत जानकारी
2.	Place/State स्थान/राज्य *
3.	Gender लिंग *
	Mark only one oval.
	Male । पुरुष
	Female महिला Other अन्य
4.	If other, please specify यदि अन्य है, तो कृपया निर्दिष्ट करें
5.	Age। उम्र *
	Mark only one oval.
	Below 20 years 20 वर्ष से कम
	Between 20-30 years 20-30 वर्ष के बीच
	Between 30-40 years 30-40 वर्ष के बीच
	Between 40-50 years 40-50 वर्ष के बीच
	Above 50 years 50 वर्ष से अधिक

6.	What is your disorder/disability? आपका विकार /विकलांगता क्या है ? 🔹	
	Mark only one oval.	
	Multiple Sclerosis मल्टिपल स्क्लेरोसिस Haemophilia हीमोफिलिया Thalassemia थैलेसीमिया Sickle cell disease सिकेल सेल Parkinson's disease पार्किसंस Other:	
7.	Is your disability visible? क्या आपकी विकलांगता दिखाई देती है?*	
	Mark only one oval.	
	Yes । हाँ	
	ा No । नहीं	
8.	At what age were you diagnosed with the disorder/disability? किस उम्र में आपको अपने विकार/विकलांगता का पता चला ?	*
	Mark only one oval.	
	Below 20 years 20 वर्ष से कम	
	Between 20-30 years 20-30 वर्ष के बीच	
	Between 30-40 years 30-40 वर्ष के बीच	
	Above 40 years 40 वर्ष से अधिक	
9.	Do you have a Disability certificate or UDID? क्या आपके पास विकलांगता प्रमाण पत्र या यूडीआयडी है?	
	Mark only one oval.	
	Yes हॉ	
	ा No । नहीं	
	Applied, in process अप्लाई किया है, प्रक्रिया में है	
10.	If you have a Disability certificate /UDID, what is the percentage of your Disability? यदि आपके पास विकलांगता प्रमाण पत्र या यूडीआयडी है तो आपकी विकलांगता का प्रतिशत क्या है?	
	Mark only one oval.	
	0-40%	
	Between 40-60% 40-60% के बीच	
	Above 60% 60% से अधिक	

11.	What is the status of your employment? । आपकी रोजगार की क्या स्थिति है?*
	Mark only one oval.
	Employed कार्यरत
	Unemployed । बेरोजगार
12.	If employed, which sector ? यदि आप कार्यरत हैं, तो आप किस क्षेत्र में कार्यरत हैं ?
	Mark only one oval.
	Public sector सरकारी विभाग
	Private sector निजी क्षेत्र
	Oovernment sector । सरकारी क्षेत्र
	Self employed स्वरोजगार
	Other:
13.	If employed, have you disclosed your disability to the employer? यदि आप कार्यस्त है तो क्या आपने मालिक से अपनी विकलांगता का खुलासा किया है? Mark only one oval. Yes हाँ No नहीं Don't want to disclose नहीं बताना चाहते
14.	If don't want to disclose, why?। यदि नहीं बताना चाहते तो क्यों ?
15.	Are you aware of Reasonable Acomodation mentioned in Chapter 4, Section 20 * of the RPWD Act 2016? क्या आप विकलांग व्यक्तियों के अधिकार अधिनियम 2016 के अध्याय 4, धारा 20 में उल्लिखित उचित आवास के बारे में जानते हैं?
	Mark only one oval.
	Yes ∣ हाँ
	○ No । नहीं

