



**GURU GOBIND SINGH INDRAPRASTHA
UNIVERSITY**

Sec 16 C Dwarka New Delhi



UNIVERSITY INCLUSION AND ACCESSIBILITY CELL UIAC-UTTHAAN

in Collaboration with

University School of Management Studies (USMS)

INCLUSION & ACCESSIBILITY(I&A) E-MAGAZINE

Volume 9

*being launched on
23rd Sept 2024
to celebrate*

INTERNATIONAL DAY OF SIGN LANGUAGES



Interview With Puneet Singh Singhal

Life Experiences of Chetan Upadhyay

Cover Story: Family of Disabled

Editor's Note By:

Prof. (Dr.) Shalini Garg

Editor-in-Chief I&A E-Magazine

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GGSIIP University, Delhi

**MESSAGE FROM
PROF. (DR.) MAHESH VERMA,
VICE CHANCELLOR, GGSIPU**



I am delighted to announce that University Inclusion & Accessibility Cell (UIAC-UTTHAAN) of Guru Gobind Singh Indraprastha University (GGSIPU), Delhi, is publishing the Ninth issue of its Biannual 'Inclusion & Accessibility' e- Magazine (2024). My best wishes go out to the dedicated editorial team on this occasion. I wish the release of the Ninth issue 'Inclusion & Accessibility' e-Magazine (2024) a grand success.

**EDITOR'S NOTE by
PROF. (Dr) SHALINI GARG
EDITOR-IN-CHIEF I&A E-Magazine**



Namaskar!

It is with great pride and enthusiasm that I present the Ninth Volume of the *Inclusion and Accessibility (I&A) E-Magazine*, a biannual publication from the University Inclusion and Accessibility Cell (UIAC UTTHAAN) at Guru Gobind Singh Indraprastha University, Dwarka, New Delhi. This edition reflects my commitment to advancing the conversation on inclusion and accessibility, highlighting key issues, personal stories, and thoughtful contributions that encourage greater awareness and engagement in creating inclusive spaces.

I am delighted to release this Special Issue of I&A e-Magazine Volume 9 and celebrate the International Day of Sign Languages, a day that holds great significance in our shared pursuit of an inclusive world. Observed globally on September 23rd, this day is a reminder of the essential role that sign languages play in ensuring equality, human rights, and communication access for the Deaf and Hard of Hearing communities. By recognizing and promoting Indian Sign Language (ISL), we honor the rich cultural diversity of sign languages and strive towards a future where barriers to communication and understanding are diminished. Let us join hands in raising awareness about the importance of sign languages in empowering individuals, breaking stereotypes, and fostering inclusive environments.

At the heart of this volume is the Cover Story on *Family of Disabled (FOD)*, a registered voluntary organization that has been serving individuals with disabilities since 1992. FOD's cross-disability approach allows them to provide support to people with a range of disabilities, addressing their diverse needs. I am excited to share an Interview with Puneet Singh Singhal, a dedicated advocate for disability rights. Puneet's personal account of living with a stammer is both insightful and inspiring. His candid reflection on how these experiences shaped his path to self-acceptance is a testament to his resilience and determination to not only overcome his personal challenges but also to advocate for others facing similar barriers. Another notable feature is the Life Experiences of Chetan Upadhyay, the recipient of the prestigious State Award in 2023. His powerful message underscores the fact that while physical disabilities may exist, the true essence of

overcoming challenges lies in mental fortitude and self-belief. He reminds us that dreams, dedication, and perseverance ultimately guide us toward success. His story serves as a beacon of hope, emphasizing that no matter the circumstances, it is our inner strength that defines our potential and ability to achieve our goals.

I would like to extend my heartfelt thanks to all for graciously sharing their stories in the cover feature, interview, and life experience sections. Your openness, courage, and insight offer readers invaluable perspectives on the realities and triumphs of living with disabilities.

This edition also includes Articles Contributed by GGSIPU Fraternity, showcasing the academic and intellectual engagement of my university's scholars, students, and staff.

Additionally, I have included Updates and News from the world of disability inclusion, offering readers the latest insights into policy changes, technological innovations, and impactful initiatives being carried out across the globe.

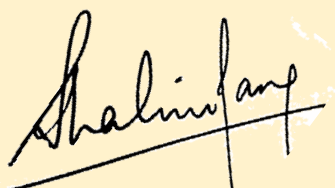
To make the reading experience more interactive, Let's Test Your Disability Inclusion Quotient (DIQ); an engaging quiz challenges readers to assess their knowledge of disability inclusion, encouraging reflection on key concepts and practices that define inclusive environments.

I would like to take this opportunity to extend my heartfelt gratitude to the Student Coordination & Design Team, whose creativity and hard work have been instrumental in bringing this edition to life. I also express my sincere appreciation to all the authors who have contributed their views, ideas, and expertise. Their dedication to the cause of disability inclusion continues to inspire and motivate efforts to create a more inclusive educational landscape.

As always, I encourage you to stay connected on social media platforms, where I share updates, submission guidelines, and information on upcoming editions. I look forward to your continuous engagement with the *Inclusion and Accessibility (I&A) E-Magazine* as I collectively work toward fostering an environment of inclusive growth and development for persons with disabilities.

I trust you will find this edition both informative and thought-provoking. Your feedback is invaluable as I continue to evolve and strengthen this platform.

Until next time, stay happy, safe, and healthy.



Prof. (Dr.) Shalini Garg

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Cover Story: Family of Disabled (Non-profit organization in Delhi)

Vision: Every person with a disability to lead a dignified, financially secure, and productive life.

Mission: To build and nurture the capacities of persons with disabilities through different sustainable interventions for improving their quality of life, making them self-reliant, and facilitating their mainstreaming.

History and Background

Family of Disabled was founded by Dr. Rajinder Johar in 1992, after sustaining an injury to his cervical spine that rendered him quadriplegic (paralysis of all four limbs) for life. Prior to this, he worked as an occupational therapist with King George's Medical College, Lucknow, Uttar Pradesh for 20 years, where his work encompassed rehabilitating people with permanent and temporary disabilities. However, in his own words,

“As a rehabilitation professional, I never thought about the life of my patient once he had left my room, my services were limited to attending and addressing his medical needs. But after acquiring disability myself and being awarded a 100% disability certificate, and confined to bed; I thought that God hasn't taken my life yet, there must be reason behind my surviving the accident. I had studied rehabilitation, I had practiced it and headed the Rehab Department for years, however, now I was not in a condition to even touch my patient and diagnose the problem, which is extremely crucial for treating your patient.

But instead of merely sympathising now I could empathise with the disabled people and decided to utilize my remaining faculties optimally to the advantage of disabled brethren.”

It was only that he wasn't a biological father of FOD; he nurtured the organization like his own baby. FOD reached great heights, received great regards, honour, and innumerable awards for its exclusive services to people with disabilities under his remarkable leadership. The most unique programmes of FOD are his brainchild, which continue to provide relief to numerous people with disabilities. His passion, grit, and determination helped FOD succeed by leaps and bounds. He not only turned the tables on his disability but was a shining living example to the countless disabled as well as non-disabled individuals who came to visit him from far and near. Though he is not physically present among us anymore but would continue to inspire millions with the life he led. He breathed his last on 1st February, 2018; we strongly believe that he is with us in spirit and would continue to guide and bless us as we take his grand legacy forward.

Key Programmes

Aids and appliances, since 1996: This programme aims to improve the mobility and/or work efficiency of people with various disabilities. FOD has been providing aids and appliances like wheelchairs- adult as well as paediatric, crutches, hearing aids, tricycles, walking sticks, walkers, sewing machines, iPods, reading glasses, telescope, rollators, pushchairs, diapers, etc. free of cost to people with disabilities, who cannot afford them,

to assist their daily living. These are given to the recipient only after thorough verification - with preference to students, petty traders, and those in jobs. To date, over 2200 individuals with different disabilities have been provided gadgets as per their requirements, in Delhi.

Apna Rozgaar Scheme, since 1998: With negligible job opportunities available to poor, illiterate, and unskilled disabled people constituting over 90% of the disabled population in India, FOD offers economic rehabilitation through its flagship programme- Apna Rozgaar Scheme (ARS). Under this scheme, persons with disabilities are given interest-free loans in kind, with which they are initiated into self-employment or helped in expanding/ diversifying their existing petty trades. By extending them financial, physical and moral support so that they can have a micro trade of their choice, this scheme aims to alleviate poverty, reduce unemployment and include them in mainstream society. FOD helps in commencing the incumbent's business by investing a small amount of Rs. 8500/pp. To date, over 1200 needy and deserving disabled individuals in Delhi have been initiated into ARS, with a success rate of over 80 percent. FOD is the only organization in Delhi, that started focusing on the economic independence of disabled people, in this very unique way as early as 1998. Even literate and vocationally skilled disabled people, who could not find a suitable job, have also availed the facility of ARS to sustain their families. Through this scheme, FOD has been able to metamorphose the lives of disabled individuals and those of their dependents. After joining ARS, they are earning anything between Rs. 7000/- to even Rs. 25,000/- per month. With a raised standard of living and established micro trade of their own, they are now providing better education to their children, good housing and medical facilities to their families, and managing to fulfill their other responsibilities towards their family and leading a life of dignity, self-confidence and self-reliance.

Beyond Limits, art exhibitions, since 2001: As FOD discovered the abundant talent and creativity among the artists with disabilities, who were opportunity deprived, FOD launched 'Beyond Limits', national level exhibitions of the artworks held annually at Arpana Art Gallery, Academy of Fine Arts & Literature, New Delhi. Through 'Beyond Limits', over 200 artists with disabilities, both amateur as well as trained, from different parts of India, have been given an opportunity to reach out to people with their imagination and creativity. Apart from monetary gains, it has helped them earn public recognition and appreciation. Many of the participating artists are the first-timers living in oblivion.

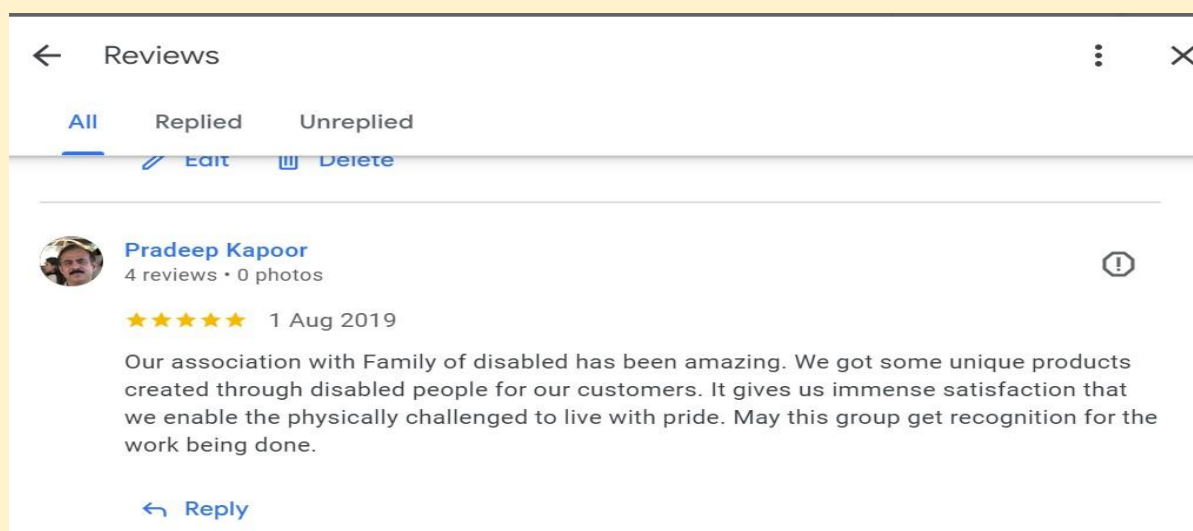
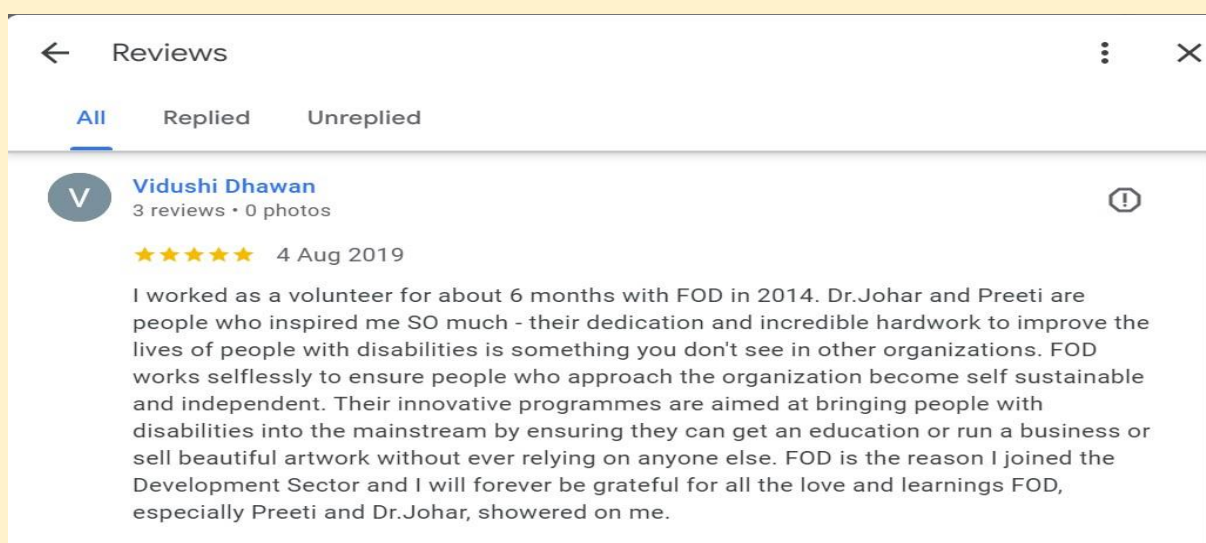
Gyan Path, 2006: Nothing can swap the importance of academics and this was unambiguously understood at FOD. A disabled person, if well-armed with education, can make a decent living. It is the only way to an inclusive society. *Gyan Path* aims to educate disabled students, primarily girls. Initially, wards of disabled parent(s) were also supported. Presently too, wards of severely disabled parents who cannot earn education expenditure on monthly tuition fees, books, stationery and uniforms is borne by the organisation. The needed financial assistance is being given from nursery to postgraduate level including short-term professional courses. 115 students have been helped and sponsored to attain education.

FOD has received 27 awards through its founder, for its exemplary work. The Founder was also featured in the Aamir Khan's reality show Satyamev Jayate, Season 1, where they wished to showcase the personality which emerged successfuldefying all odds and surmounting all challenges.

Prior to this, FOD was running all its programmes from the founder's home. Featuring in Satyamev Jayate helped FOD in reaching reach out to the Indian citizens, who contributed generously for the cause and FOD could build its own Multi-Purpose Rehab Centre in Najafgarh, New Delhi. At this Centre, FOD has a training -cum-production unit of pencils made from newspapers, cutting & tailoring unit,basic computer skills, upcycling unit, etc.

Future Plans

- 1) Bringing the art online- we are working on an exclusive website for promotion of fine arts by artists with disabilities.
- 2) Bakery unit- We are trying our recipes and we hope to bake healthy and delicious cookies and muffins by involving bakers with disabilities to increase livelihood.





Interview With Puneet Singh Singhal, Disability Inclusion and Accessibility Advocate

- 1. How did your experiences with stammering shape your approach to public speaking and advocacy, and what techniques have you found most effective in managing public speaking anxiety?**

My journey with stammering has deeply influenced my approach to public speaking and advocacy. Stammering taught me the power of vulnerability and authenticity, which I now embrace in every public engagement. I focus on connecting with the audience on a human level, sharing my story openly to create a space where others feel safe to share theirs. Techniques that have helped me manage public speaking anxiety include mindfulness, deep breathing, and grounding myself in the purpose of my message rather than the perfection of my delivery. I remind myself that my voice, though different, carries value and meaning.



- 2. What are the most significant societal changes you've observed regarding the understanding and acceptance of stammering, and what further steps need to be taken?**

Over the years, I've noticed a gradual shift in society's understanding and acceptance of stammering. There's more awareness now that stammering is not just a speech issue but a communication difference that deserves respect. However, there is still a long way to go. Society needs to move beyond mere tolerance to active inclusion, creating spaces where people who stammer are encouraged to express themselves fully. This involves rethinking how we view communication success, and recognizing that fluency does not equate to clarity or intelligence. Educational campaigns, media representation, and inclusive communication practices in workplaces and schools are crucial next steps.

- 3. Can you share how your experiences with dyslexia have influenced your approach to learning and problem-solving in your advocacy work?**

Dyslexia has significantly influenced my approach to learning and problem-solving. The challenges I've faced with reading and traditional forms of learning pushed me to seek out alternative methods of understanding and processing information. I've developed a strong reliance on visual aids, hands-on experiences, and storytelling, which have become integral to how I learn and teach others. Dyslexia has also fostered my ability to think creatively and approach problems from multiple perspectives. Rather than seeing dyslexia as a limitation, I view it as a unique lens that allows me to see connections and solutions that others might overlook, which has greatly enriched my advocacy work.



4. What unique challenges and strengths have you encountered as a result of dyspraxia, and how have these shaped your career and personal growth?

Dyspraxia has presented unique challenges, particularly with coordination, motor skills, and tasks that require fine motor control. These difficulties have taught me patience, persistence, and the importance of finding alternative ways to achieve my goals. Despite the challenges, dyspraxia has also been a source of strength, cultivating a deep sense of empathy and resilience. It has pushed me to be more organized and strategic in my work, ensuring that I can manage tasks effectively. These experiences have shaped my career by making me a more adaptable and creative leader, someone who is not afraid to approach problems from unconventional angles and who values the diverse abilities of others. Dyspraxia has instilled in me a commitment to inclusivity, driving my passion for creating environments where everyone, regardless of their challenges, can thrive.

5. Green Disability integrates climate action with disability rights. How do you envision this initiative transforming the global climate discourse, particularly for marginalized communities?

Green Disability aims to transform the global climate discourse by ensuring that the voices and needs of persons with disabilities (PWDs) are not only included but are central to climate action. Marginalized communities, especially PWDs, are often the most affected by climate change, yet their perspectives are rarely considered. By integrating disability rights into climate strategies, we can create more inclusive, effective solutions that address the intersectional challenges these communities face. This initiative is about shifting the narrative from one of vulnerability to one of empowerment, showing that PWDs are key stakeholders in the fight against climate change.

6. How are you leveraging AI-based arts for storytelling to amplify the voices of persons with disabilities, and what impact do you hope to achieve through this innovative approach?

Leveraging AI-based arts for storytelling allows us to create compelling, accessible narratives that resonate on a deep, emotional level. Through AI, we can generate visuals, audio, and interactive content that highlight the lived experiences of persons with disabilities (PWDs) in a way that traditional media often cannot. This approach not only amplifies their voices but also bridges the gap between different audiences, making the stories more relatable and impactful. The goal is to foster empathy, drive policy change, and create a cultural shift that values and prioritizes inclusivity in both environmental and social contexts.



7. Building a global network like GNYPWD requires deep community engagement. What strategies have you found most effective in creating a cohesive, supportive, and active community across diverse cultures and geographies?

Building the Global Network of Young Persons with Disabilities (GNYPWD) has been a journey of deep listening, respect, and shared purpose. The most effective strategies include fostering an environment of trust and mutual respect, where every member feels valued and heard. We emphasize open communication, cultural sensitivity, and the importance of shared goals. Regular virtual meetings, collaborative projects, and a focus on storytelling have helped bridge geographical and cultural gaps, creating a sense of unity and collective action. By highlighting our common challenges and aspirations, we've built a network that is not just active but also resilient and supportive.

8. What role do you believe technology plays in advancing accessibility, and how can it be improved?

Technology is a powerful tool in advancing accessibility, offering innovative solutions that break down barriers for persons with disabilities. However, to maximize its potential, technology

must be developed with inclusivity at its core. This means involving PWDs in the design and testing phases, ensuring that tech solutions are not only usable but also enhance their quality of life. Improvements can be made by prioritizing universal design principles, increasing affordability, and expanding access to digital literacy training for PWDs. The future of technology in accessibility lies in its ability to adapt to diverse needs and create equal opportunities for all.

9. In what ways do you think society can become more inclusive and supportive of people with disabilities?

Society can become more inclusive and supportive of people with disabilities by first acknowledging that disability is a natural part of human diversity. This requires a cultural shift from viewing disability as a deficit to recognizing it as a difference that enriches our communities. Education plays a key role in this transformation, with schools, workplaces, and media needing to portray disabilities accurately and positively. Policy changes are also crucial, ensuring that PWDs have equal access to education, employment, and public spaces. Ultimately, inclusion requires active participation from all sectors of society, creating environments where PWDs are not just accommodated but celebrated.

10. How would you describe the concept of 'public speaking anxiety,' and how have you personally navigated it?

Public speaking anxiety is the fear or nervousness that arises when one is about to speak in front of an audience. For many, including myself, this anxiety can be heightened by the fear of being judged or misunderstood. Navigating this anxiety has been a journey of self-acceptance and purpose-driven action. By focusing on the message rather than the mechanics of delivery, I've learned to channel my anxiety into passion. Techniques like mindfulness, preparation, and embracing my unique voice have allowed me to transform what was once a challenge into a powerful tool for advocacy and connection.

Life Experiences of Chetan Upadhyay, Professional Wheelchair Dancer

Personal Stories of Triumph and Resilience

2013 तक मैं एक ग्रुप के साथ काम कर रहा था, जहाँ मैं न केवल परफॉर्मेंस देता था, बल्कि बहुत कुछ सीखता भी था। उस समय मुझे कुछ आर्थिक सहयोग मिल जाता था, लेकिन मेरा मुख्य उद्देश्य डांस को बेहतर तरीके से सीखना था। कुछ कारणों से मुझे वह ग्रुप छोड़ना पड़ा, लेकिन मैंने यह ठान लिया कि मैं डांस नहीं छोड़ूंगा। उस समय कोई ऐसा दिव्यांग डांस ग्रुप भी नहीं था जहाँ मैं जाकर शामिल हो सकूँ और सीखता रहूँ। तब मैंने निर्णय लिया कि मैं अपना खुद का डांस ग्रुप बनाऊंगा। मैंने अपने स्कूल के कुछ दिव्यांग दोस्तों से संपर्क किया जो डांस में रुचि रखते थे। हमने पांच लोगों के साथ अपने ग्रुप की शुरुआत की। शुरुआती दिनों में हमें प्रैक्टिस के लिए जगह नहीं मिल रही थी, लेकिन हमने हिम्मत नहीं हारी। मैंने अपने स्कूल के प्रिंसिपल से अनुमति लेकर, हर संडे बास्केटबॉल कोर्ट में प्रैक्टिस करना शुरू



किया। 2014 में हमें अपना पहला मौका मिला और हमने सोनी टीवी के रियलिटी शो पर अपनी पहली परफॉर्मेंस दी। हालांकि, हमें कमर्शियल प्रोग्राम्स मिलने में कठिनाइयों का सामना करना पड़ा क्योंकि हमें नहीं पता था कि किस प्रकार से आयोजकों से संपर्क किया जाए। फिर भी, हम इवेंट मैनेजर्स और अपने कनेक्शंस में जो लोग थे, उनसे संपर्क करते रहे। शुरुआत में हमें केवल साल में 2-3 कार्यक्रम मिल पाते थे। 2015-16 में एक डांस ग्रुप ने हमारे साथ कोलैबोरेशन का प्रस्ताव दिया। नाम उनके ग्रुप का होगा, लेकिन परफॉर्मेंस हमारी टीम की होगी। हमें नियमित कार्यक्रमों की जरूरत थी, इसलिए हमने यह प्रस्ताव स्वीकार किया। इस दौरान हमने स्किल इंडिया, वंदे भारतम, अबू अवार्ड्स, और रूस में इंटरनेशनल परफॉर्मेंस जैसी जगहों पर प्रस्तुति दी। 2020 की शुरुआत से लेकर अगस्त 2021 तक, कोविड के कारण हमारे पास एक भी कार्यक्रम नहीं था। यह हमारे लिए कठिन समय था, क्योंकि कोई भी इवेंट नहीं हो रहे थे। अगस्त 2021 में "हर घर तिरंगा" कार्यक्रम के साथ हमारी शुरुआत हुई, और उस साल के अंत तक हमने पांच प्रोग्राम किए। इसके बाद, हमने मार्केट में अपने ग्रुप को और प्रमोट करना शुरू किया, ताकि अधिक से अधिक लोगों को हमारे बारे में पता चल सके। मैंने यह भी सीखा कि हमें कौन सी

ऑडियंस को टारगेट करना चाहिए और कहां-कहां परफॉर्मेंस के लिए संपर्क करना चाहिए। इससे हमें सकारात्मक प्रतिक्रिया मिलने लगी और हमारे कार्यक्रमों में बढ़ोतरी हुई। हमने दिव्या कला मेला, दिव्या कला शक्ति, पर्पल फेस्ट, और दिव्या उत्सव जैसे बड़े कार्यक्रमों में भाग लिया, जिससे हमारे ग्रुप की पहचान और मजबूत हुई।

Educational and Professional Journeys

मेरी शिक्षा की शुरुआत अमर ज्योति स्कूल से हुई, और वहीं से मेरे डांस के सफर की भी शुरुआत हुई। हालांकि पढ़ाई में मैं बहुत अच्छा नहीं था, लेकिन डांस में मैं हमेशा आगे रहता था। स्कूल की ओर से मैंने कई प्रतियोगिताओं में भाग लिया, और अधिकतर में प्रथम स्थान प्राप्त किया। इसी दौरान मुझे स्कूल का बेस्ट मेल कल्चरल स्टूडेंट का अवार्ड भी मिला, जिसने मेरी कला के प्रति रुचि को और भी बढ़ा दिया। स्कूल की पढ़ाई पूरी करने के बाद भी मैंने अपनी नृत्य यात्रा को जारी रखा और एबिलिटी अनलिमिटेड फाउंडेशन ज्वाइन किया। वहां मेरे डांस के हुनर को और निखारा गया, और मुझे नई तकनीकें सीखने का मौका मिला। हालांकि, इस यात्रा में कई चुनौतियाँ थीं। शुरुआत में हमारे पास अच्छी व्हीलचेयर नहीं थी, जिसके चलते कई बार हमारे हाथों के अंगूठे घायल हो जाते थे। व्हीलचेयर की स्पिनिंग सीखते वक़्त भी कई बार चोटें

लगती थीं, खासकर सिर पर। गिरते वक़्त सबसे पहले सिर को बचाना ज़रूरी होता था, लेकिन चोट लगने का डर कभी भी हमें पीछे नहीं खींच पाया। हमने चोटों से घबराए बिना अपनी प्रैक्टिस जारी रखी और नए-नए स्टंट बनाते और करते रहे। यह कठिनाइयाँ हमें मजबूत बनाती रहीं और हमारे जुनून को और बढ़ावा देती रहीं। मेरी पेशेवर यात्रा में इन चुनौतियों ने मुझे आत्मनिर्भर और दृढ़ बनाया।



Empowerment

मेरे लिए सशक्तिकरण का मतलब है खुद को और दूसरों को अपनी पूरी क्षमता को पहचानने और उसे विकसित करने की शक्ति देना। यह एक ऐसा सफर है जहाँ व्यक्ति न केवल अपनी कमजोरियों से ऊपर उठता है, बल्कि अपनी ताकत को पहचानता है और उसे समाज में अपनी जगह बनाने के लिए उपयोग करता है। मैंने खुद को सशक्त किया और अपनी टीम के दिव्यांग कलाकारों को भी आत्मनिर्भर बनने में मदद की। हमारा मुख्य उद्देश्य था कि हम समाज में सम्मानजनक जीवन जिएं और पेशेवर दिव्यांग कलाकार के रूप में अपनी पहचान बनाएं। हमने अपनी कमजोरियों को पीछे छोड़ते हुए अपनी ताकत पर काम किया और समाज में एक सकारात्मक उदाहरण बनकर उभरे हैं। हमारी यह यात्रा न केवल हमें सशक्त करती है, बल्कि हम दूसरों को भी प्रेरित करते हैं कि दिव्यांगता कोई बाधा नहीं है। यह केवल एक नई दिशा है, जहाँ सही मार्गदर्शन और आत्मविश्वास के साथ हर चुनौती को पार किया जा सकता है।

Cultural and Social Integration

सांस्कृतिक दृष्टिकोण से, हमारी प्रस्तुतियाँ दर्शकों के लिए न केवल मनोरंजन का माध्यम होती हैं, बल्कि उन्हें आश्चर्यचकित भी करती हैं। जब दर्शक हमारी परिस्थितियों और हमारी क्षमता को देखते हैं, तो वे हमारी प्रस्तुतियों से प्रेरणा प्राप्त करते हैं। हमारा उद्देश्य केवल मनोरंजन तक सीमित नहीं है; हम अपने प्रदर्शन के माध्यम से समाज को यह संदेश देना चाहते हैं कि जीवन में किसी भी कठिनाई को बाधा मानकर रुकना नहीं चाहिए। हमारी प्रस्तुतियाँ सामाजिक रूप से एक गहरा प्रभाव छोड़ती हैं, जिससे लोगों को यह सिखने को मिलता है कि चुनौतियों का सामना कैसे किया जाए और कैसे उन्हें पार करके अपने जीवन में आगे बढ़ा जाए। हमारी टीम के सदस्यों ने अपने जीवन की मुश्किल परिस्थितियों से ऊपर उठकर यह साबित किया है कि दिव्यांगता कोई रुकावट नहीं, बल्कि एक नई दिशा है। हमारी प्रस्तुतियों से न केवल दर्शकों का मनोरंजन होता है, बल्कि उन्हें यह संदेश भी मिलता है कि संघर्षों से हार मानने की बजाय, हमें हमेशा आगे बढ़ते रहना चाहिए।



Challenges and Opportunities



चुनौतियाँ ने मुझे और मेरी टीम को बेहतर बनने की प्रेरणा दी है। डांस में न केवल मुझे खुद को मजबूत करना था, बल्कि अपनी टीम को भी आगे बढ़ाना था। सबसे बड़ी चुनौती यह थी कि हमें अपने लिए नियमित काम और कार्यक्रम ढूँढने की आवश्यकता थी, लेकिन धीरे-धीरे मैंने इस प्रक्रिया को समझा और इसका भी अंदाजा लगाना शुरू किया।

हमारी प्रस्तुतियाँ इतनी अच्छी होती थीं कि हमें हमेशा दर्शकों से पॉजिटिव प्रतिक्रिया मिलती थी, जिससे हमें और अधिक प्रेरणा मिलती थी। यह हमारे लिए बहुत खुशी का समय होता था और हमें अंदर से यह इच्छा होती थी कि हम और कुछ नया करें, जिससे हमारी ऑडियंस को हमेशा कुछ नया और आश्चर्यचकित करने वाला अनुभव मिले।

इन्हीं विचारों को ध्यान में रखते हुए, मैंने 2022 में व्हीलचेयर मोटरक्रॉस स्टंट करने की कोशिश शुरू की। लेकिन इसके लिए आवश्यक व्हीलचेयर बहुत महंगी थी। शुरुआती कीमत \$5000 थी, जिसे भारत लाना और भी अधिक महंगा पड़ता। इसलिए मैंने एक न्यू मोशन व्हीलचेयर पर इसे करने का फैसला किया। हालाँकि, इस व्हीलचेयर में प्रैक्टिस के दौरान व्हीलचेयर में समस्याएँ आनी लगीं—कभी सीट फट जाती, कभी फ्रंट फोर्क टूट जाता, तो कभी कोई और हिस्सा टेढ़ा हो जाता।

इन सब कठिनाइयों के होने के बाद, मैंने इस गेम के अनुसार व्हीलचेयर को मोडिफाई किया। जैसे व्हीलचेयर में शॉकर इंस्टॉलेशन, फिक्स्ड इंटरैस्ट साइड और फ्रंट फोर्क सस्पेंशन बनवाए, ताकि यह मेरे स्टंट्स के लिए उपयुक्त हो सके। मॉडिफिकेशन करवाते वक्त मैं कई बार सफल हो जाता था लेकिन फिर प्रयास करता था उसको सही

करने का तो बाद में रास्ता मिल ही जाता था, मैंने इस व्हीलचेयर से 5 और 7 सीढ़ियों की छलांग लगाई, और 8 फीट और 12 फीट से व्हीलचेयर झोंपिंग किया।

इतनी उपलब्धियों के बावजूद, मैं अभी भी कुछ और नए स्टंट्स को सीखने का प्रयास लगातार कर रहा हूँ, जिसमें मुझे सुधार दिखाई दे रहा है। हर नया स्टंट मेरे लिए एक नया अवसर है, और मैं अपनी क्षमताओं को और अधिक निखारने की कोशिश कर रहा हूँ।

Impact and Achievements

हमारी सबसे बड़ी उपलब्धि यह है कि हमने अपने काम और प्रदर्शन के माध्यम से समाज में एक नया दृष्टिकोण स्थापित किया है। हमने यह साबित किया है कि दिव्यांगता केवल एक शारीरिक स्थिति है, जो हमारी क्षमताओं को सीमित नहीं करती। हम दिव्यांग कलाकारों ने राष्ट्रीय और अंतरराष्ट्रीय स्तर पर मंचों पर अपनी प्रस्तुतियाँ दी हैं, जहाँ हमने न केवल वाहवाही बटोरी, बल्कि लोगों की मानसिकता में सकारात्मक बदलाव लाने का भी काम किया।

हमने कई प्रतिष्ठित रियलिटी शोज़ और बड़े कार्यक्रमों में हिस्सा लिया है, और हर बार हमने दर्शकों को यह दिखाया है कि कोई भी चुनौती इतनी बड़ी नहीं होती जिसे हिम्मत और समर्पण से पार न किया जा सके। हमारे प्रदर्शन केवल एक मनोरंजन नहीं हैं, बल्कि एक संदेश भी हैं कि सीमाएँ केवल मन की उपज हैं।

हमारी टीम न केवल अपने जीवन में सफल रही है, बल्कि हमने समाज के विभिन्न हिस्सों में प्रेरणा और परिवर्तन की लहर भी पैदा की है। हमारी प्रस्तुतियों के बाद कई दर्शकों ने हमसे कहा कि हमने उनकी सोच और दृष्टिकोण को बदल दिया है। यह हमारे लिए सबसे बड़ी उपलब्धि है कि हम न केवल अपने जीवन को बेहतर बना रहे हैं, बल्कि दूसरों के जीवन



में भी बदलाव लाने का काम कर रहे हैं।

हमारी सफलता का एक और महत्वपूर्ण पहलू यह है कि हमने दिव्यांग लोगों के लिए एक सकारात्मक रोल मॉडल बनने का काम किया है। हमने दिखाया है कि दिव्यांगता के बावजूद एक पेशेवर कलाकार के रूप में काम करना और समाज में सम्मान प्राप्त करना पूरी तरह से संभव है। यह हमारी लगातार मेहनत, जुनून, और दृढ़ संकल्प का परिणाम है कि आज हम दूसरों के लिए प्रेरणा का स्रोत हैं।

Message for the Readers

हम अपने पाठकों से यह कहना चाहेंगे कि विकलांगता केवल शरीर में होती है। अगर आप मानसिक रूप से मजबूत हैं और अपने मन में विश्वास बनाए रखते हैं, तो कोई भी बाधा आपकी सफलता के रास्ते में नहीं आ सकती। आपके सपने और आपकी मेहनत ही आपको आपके मुकाम तक पहुंचा सकते हैं। हमें खुद पर भरोसा होना चाहिए कि हम कुछ भी कर सकते हैं, चाहे हमारी परिस्थिति कैसी भी हो। यदि आप अपने मन से हार नहीं मानते, तो आप निश्चित रूप से अपने जीवन में बेहतर कर सकते हैं और अपने लक्ष्यों को हासिल कर सकते हैं।



Chetan Upadhyay is State Award winner in 2023



Bridging the Gap: Disability Inclusion, Accessibility, and Building a Fairer Society”

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Introduction: Disability Inclusion and Accessibility

"DISABLES ARE THE POOREST OF POORS" Not because of their disabilities but the inequalities and inaccessibility of resources to them at par with normal people. They are seen as destitute and often neglected in their families, schools and lately occupy the back seat in governance as well. A report of UNICEF discloses 49 percent of disable children have never seen school in their lifetime. But as we say "BETTER LATE THAN NEVER" We evolve and thrive as a society better than before, millennium goals now known as SDG 2015 have included SDG goal10 of REDUCED INEQUALITIES and SDG 16 PEACE and JUSTICE. On the lines of which today in India we have public shauchalayas with ramp, special Schools for special children, inclusive courts are worth appreciating the effort. It reminds us that equitable and non-discriminatory societies can give us more medals at Paralympics than the Olympics and a burgeoning entrepreneur like Srikanth Bolla who with inability to see doesn't do well for themselves but also for people alike them with a vision far better than people with eyes, if given a unprejudiced hunting ground can bring about substantial change.

IMPORTANCE OF DISABILITY INCLUSION AND ACCESSIBILITY

Disability inclusion and accessibility are very important not only for society but also for businesses. An inclusive work environment is one that values and respects diversity, creating a space where all individuals feel respected and welcomed. Everyone is given equal and same opportunities for growth and development within the organization. On the other hand, accessibility ensures that physical spaces, services, and digital platforms are modified as per the needs of people with disabilities.

It is not just a social responsibility but a very smart business strategy. Companies that invest in disability inclusion and accessibility often enjoy several benefits, such as increased creativity, productivity, and innovation. They also benefit from a better work culture and environment, which further helps in building a good reputation and brand image.

Support Services and Resources

People are frequently judged in our society primarily by someone's outward look than their inner qualities. There is a popular notion in our society that how can people with disabilities be mentally healthy and why do they need to go into education or any other field. It is important to remember, though, that a person's physical attributes or body never define their capabilities. And the best example of this is DM Suhas Lalinakere Yathiraj who won silver medals at the Tokyo Paralympics 2020 and Paris Paralympics 2024 Games and thus

became the only Indian para-badminton player to win consecutive medals in sports. Dr Suresh H Advani, who was afflicted with polio at the age of 8, is credited with being the pioneer of hematopoietic stem cell transplantation in India and has been awarded the Padma Vibhushan by the Government of India. By looking at these two examples, we understand that whether it is sports or education, disability cannot stop you in any field. And it is not only important for disabled people to understand this, but it is also important for people like us who find it difficult to understand this.

Today here we are discussing about Disability inclusion and accessibility as broader prospective which means that there will be an equal opportunity everywhere, irrespective of their physical disability. In June 2019, the United Nations launched the Disability Inclusion Strategy with the aim of enabling disabled

people to play their role in every field It was being done as the part of Sustainable Development Goals (SDGs) targets by 2030. According to the initial research of United Nations on Sustainable Development Goals (SDGs) that publish in the report “Disability and Development Report 2023” which indicate that World is highly off track in achieving the target under SDGs for people with disabilities. To tackle the

situation first we need to understand the challenges which made world so off track for people with disabilities. In August 2023 General secretary of United Nations has submitted the final report on the step taken by the UN to apply United Nations Disability Inclusion Strategy in 2022. This step can prove to be a milestone in bringing disability inclusion and accessibility to every corner of the world.

KEY ELEMENTS OF DISABILITY INCLUSION

- **Accessibility:** Accessibility means removing all those barriers that prevent disabled people from participating in everyday activities. It includes both physical accessibility and accessibility to information and communication technology.
- **Education:** Education is a very important element for disability inclusion. Disabled children rarely complete primary school, with only 9% completing secondary school. The 2011 census data shows that in rural areas, 49% of the disabled population is literate, while it is 67% in urban areas. So, it is important to have inclusive education, as the employability of people with disabilities depends on their education. The schools should provide the children with disabilities with both physical access and a supportive environment.
- **Employment:** Disability inclusion in the workforce is essential to achieving economic independence and dignity for individuals with disabilities. In India, around 1.3 crore people with disabilities are employable, but only 34 lakh of them
- economic development and also of the country. They should be provided with supportive work environments, equal opportunities, and flexible policies.
- **Healthcare:** People with disabilities often face difficulty in accessing healthcare services. Inclusion in healthcare services involves acknowledging and addressing the needs and perspectives of people with disabilities. It must focus on providing accessible facilities, training healthcare providers to accommodate different disabilities, and ensuring that people with disabilities have the same health outcomes as the general population.
- **Legal Protection and Advocacy:** Policies and laws, such as the Rights of Persons with Disabilities Act, 2016 and the Legal Services Authorities Act, 1987, are critical in ensuring the rights of individuals with disabilities. Many advocacy groups also continue to work toward improving legal protections to reduce discrimination.

IMPORTANCE OF SHIFTING ATTITUDES

One of the largest obstacles to disability inclusion is the societal perception and misconceptions surrounding disabilities. Often, people with disabilities are seen through the lens of what they cannot do rather than their unique abilities. So, it has become important to shift the societal attitude from a charity-based model to a rights-based model. According to the social model of disability, it is not the disability itself that limits individuals but rather the societal and environmental structures that do not accommodate diverse needs. Shifting attitudes toward disability is very important as it can help improve the lives of persons with disabilities, which will further lead to a more inclusive society. It should be noted that not every disability is visible. So, the first step should be to not judge anyone. We can achieve the idea of an inclusive society by eradicating discrimination, improving perceptions of people, raising awareness regarding different types of disabilities, and considering our words and actions.

ROLE OF TECHNOLOGY

Technology has played a huge role in transforming the lives of people with disabilities by making day-to-day activities, education, and employment more accessible. From smart devices to assistive technologies, innovations are bridging the gap between people with disabilities and the wider world.

- **Assistive Devices:** These are tools that help people with disabilities perform tasks they may otherwise find difficult. For example, screen readers assist visually impaired individuals by reading aloud the text on a screen, while hearing aids and easily. Additionally, mobility aids like electric wheelchairs or prosthetic limbs provide independence to individuals with physical disabilities.
- **Digital Accessibility:** The digital world has become a key area where technology drives inclusion. Websites, apps, and digital platforms are now being designed with accessibility features like voice recognition, text-to-speech, and closed captions, ensuring that users with disabilities can navigate them without barriers. The rise of virtual assistants (like Siri or Google Assistant) allows people with disabilities to complete tasks using only their voice.
- **Remote Work & Education:** The widespread adoption of remote work and online learning, especially during the COVID-19 pandemic, has opened new doors for people with disabilities. With flexible schedules, the need for physical commutes has been reduced, and virtual meetings have become a standard way to participate in work and education. However, continued efforts to ensure that all digital tools remain accessible are necessary.

The Future of Disability Inclusion

The future of disability inclusion looks promising, but it requires ongoing efforts from society, businesses, and policymakers. Here's what we might see in the coming years:

- **Increased Use of AI:** Artificial Intelligence (AI) can further revolutionize accessibility. For example, AI can be used to create personalized learning systems for students with disabilities, adjust content to suit individual needs, and improve job matching for people with disabilities based on their unique abilities.
- **Smart Cities:** Cities of the future may be built with inclusivity in mind. Smart cities, which use technology to improve urban life, could include features such as accessible transportation systems, apps that assist in navigation for the visually impaired, or automatic door openers in public buildings. These innovations would make cities more accessible and welcoming for people with disabilities.
- **More Inclusive Workplaces:** As awareness grows, more companies are likely to adopt inclusive hiring practices, making workplaces friendlier to people with disabilities. The concept of "workplace accommodation" may evolve further, incorporating flexible working arrangements and the use of adaptive technology to ensure equal opportunities.
- **Stronger Legal Frameworks:** Governments around the world are beginning to strengthen laws related to disability rights, ensuring that people with disabilities are protected from discrimination and have access to public spaces, education, and norm.

In short, technology and social progress will continue to drive disability inclusion forward. With the right innovations and policies, the future will hopefully be one where individuals with disabilities face fewer barriers and have greater opportunities to contribute fully to society.

CONCLUSION: DISABILITY INCLUSION AND ACCESSIBILITY

Ensuring disability inclusion and accessibility is not just a moral responsibility, but also a practical necessity in building a fair and equitable society. When spaces, services, and opportunities are

accessible to all, we empower individuals with disabilities to fully participate in all aspects of life—whether it's education, work, or social engagement. This promotes independence, dignity, and respect. Governments, businesses, and communities must work collaboratively to remove physical, digital, and social barriers. Adopting inclusive policies, investing in assistive technologies, and fostering a culture of acceptance are all vital steps toward creating an environment where everyone, regardless of ability, can thrive. Ultimately, disability inclusion benefits everyone. By designing systems and

structures that accommodate diverse needs, we foster innovation and resilience, while creating a more compassionate and inclusive world for future generations. Achieving true accessibility is not an endpoint, but an ongoing commitment to adapt and improve, ensuring that no one is left behind.

Governments around the world have implemented various policies to promote disability inclusion and accessibility, recognizing the importance of creating equal opportunities for people with disabilities.

- **The Americans with Disabilities Act (ADA) – United States:** One of the most comprehensive pieces of legislation, the ADA prohibits discrimination against individuals with disabilities in areas like employment, transportation, public accommodations, and telecommunications. It ensures that public and private spaces are accessible, requiring businesses and government agencies to provide reasonable accommodations.
- **Disability Discrimination Act (DDA) – United Kingdom:** This act made it illegal for employers, service providers, and public bodies to discriminate against people based on their disabilities. Over time, the DDA has evolved into the Equality Act of -discrimination laws, further expanding disability protections.
- **National Policy on Disabilities – Australia:** Australia's national framework emphasizes promoting access to mainstream services for people with disabilities, focusing on employment, education, and healthcare. The National Disability Insurance Scheme (NDIS) is a landmark program that provides funding for services and support, tailored to the individual needs of people with disabilities.
- **Accessible Canada Act (ACA) – Canada:** Introduced in 2019, the ACA is designed to eliminate barriers in areas under federal jurisdiction, such as banking, telecommunications, and transportation. The goal is to make Canada barrier-free by 2040, with organizations being required to create and implement accessibility plans and involve people with disabilities in their development.
- **Rights of Persons with Disabilities Act – India:** This legislation was passed in 2016 and includes provisions to protect the rights of people with disabilities, ensuring their access to education, employment, healthcare, and public transportation. The act also mandates that government and private sector institutions make necessary adaptations to provide equal access.

These policies reflect a growing global commitment to creating inclusive societies, but continued effort is needed to ensure that their implementation keeps pace with evolving needs and technologies. Collaboration between governments, communities, and organizations is key to creating environments where individuals with disabilities can thrive.

“Disability Inclusion and Accessibility: Towards a Developing & Inclusive Society for All”

by Narender Kumar and Yashica Garg, MBA (USMS), GGSIPU.

Disability inclusion and accessibility are important elements of building social cohesion. The effort to create a more inclusive world is not about building ramps or providing basic amenities; it is about creating an environment where everyone, regardless of their wealth, can thrive in many places, including students, employees, friends, community members, patients, spouses, partners or parents for a few. This article will examine several subtopics, including teaching and learning, services and resources, policies and procedures, relationships and culture, health, intersectionality and diversity, and legal and policy issues. Together, these elements form the building blocks of a larger world.



The inclusion and accessibility of people with disabilities is essential to creating a just and fair society. The aim is not to provide facilities or resources but to create an environment where everyone can thrive, regardless of ability. True inclusion goes beyond physical infrastructure to include inclusive education, services and services, social, health, intersectional, and legal issues. These interactions form the basis of a positive approach to disability inclusion and accessibility.

Training & Development

Inclusive teaching and learning are critical to creating a learning environment that works for all students, including students with disabilities. These practices go beyond simply providing physical access; they include rethinking how education is delivered to ensure it is accessible to all. By incorporating Universal Design for Learning (UDL) principles, educators can create a flexible learning environment that adapts to different needs. UDL emphasizes providing a variety of activities, instruction, and directions to ensure that all students, regardless of their physical, emotional, or intellectual abilities, receive a quality education. Changing the curriculum, teaching methods, and assessment methods are important steps toward achieving

this goal.

Supportive services and resources play a key role in creating a cohesive system. This includes technology services such as screen readers, Braille displays, wheelchairs, and hearing aids, as well as support services such as translation, writing services, and education. However, providing these resources is not enough. Organizations and institutions must actively raise awareness of support services and work to reduce the stigma associated with seeking help. Ensuring that people with disabilities understand how to access these services is an important part of the inclusion process.

India & its Policy

In the case of India, in 2006, the government of India enacted a national policy for the treatment of persons with disabilities in India, which recognizes persons with disabilities as a significant resource of the country and works to create an environment that ensures their equality, rights and full participation in society. The Department for the Empowerment of Persons with Disabilities (DEPwD) embodies its commitment to creating an inclusive society where persons with disabilities (Divyangjans) can live productive, safe, and meaningful lives with adequate support for their growth and development. It is based on the principles of equality, freedom, justice and dignity for all enshrined in the Constitution of India and insists on sharing that empowers everyone, including persons with disabilities. The laws of the country recognize that most persons with disabilities can live better lives if they are treated equally and adequately. To support this goal, the government has developed a system for implementing national policies. On 30 March 2007, India signed an agreement with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) to further include the disadvantaged communities. To ensure inclusion, the Ministry has adopted the Site Standards for Social Media and Accessibility in India 2021, Effective Use of ICT Equipment and Services, Uniform Accessibility Standards Specific to the Cultural Sector, Accessible Areas, Civil Aviation Accessibility Standards 2022, Accessibility Standards in Health Care and Uniform Accessibility Standards/Guidelines Specific to the Rural Sector. The approval of these guidelines by the Ministry demonstrates its commitment to ensuring universal access to services for persons with disabilities. Furthermore, collaboration with the Ministry of Telecommunications, Electronics and Information Technology and the Ministry of Law and Justice strengthens the pathway to accessibility, making every effort a good avenue for participation.

Social Inclusiveness

Community involvement is another important aspect of genuine environmental support. It involves creating a culture where people with disabilities cannot participate but are welcomed, valued and respected. This means challenging stereotypes, breaking down social barriers and encouraging interactions that foster meaningful communication. Schools should support activities such as events, clubs and sports that encourage everyone to participate. It is also important to have representation of people with disabilities in leadership roles, in the media and in public discourse to combat conflict and promote leadership. To achieve this goal, we

need the collaboration of all areas of society, from government to business, from communities to individuals. Effective medical services, psychological support, and special needs-based community services are essential to promoting health. Creating a safe space where people with disabilities can express themselves, seek care, and connect with others is essential to fostering a sense of belonging. Training health professionals to provide inclusive services, promoting

mental health awareness, peer support, and providing community services are important to promoting health. Intersectionality recognizes that people experience disability differently due to the intersection of social factors such as race, gender, sexuality, and socioeconomic status. For example, women with disabilities may face special challenges compared to men with disabilities due to social and community expectations. Similarly, individuals from ethnic or racial minorities may face additional barriers to accessing support and services. Interdisciplinary knowledge ensures that policies and practices are inclusive of all individuals and that their unique experiences and needs are acknowledged.

Legal Frameworks

Legal frameworks and policies are essential for the implementation of disability rights and accessibility. International agreements such as the United Nations Convention on the Rights of Persons with Disabilities (CRPD) have set international standards for disability inclusion. National laws such as the Americans with Disabilities Act (ADA) in the United States or the Equality Act in the United Kingdom set guidelines for equal rights and opportunities. Organizations and institutions must not only comply with these laws, but also advocate for the rights of people with disabilities and work to influence changes in national and international village laws. Ensuring that the legal system is strong, enforceable, and adaptable to changing needs is crucial to protecting the rights of people with disabilities.

Opportunity at all levels

Disability inclusion and accessibility are multifaceted issues that require a comprehensive approach that includes inclusive education, support services, inclusive policy, social, nutritional health, intersectionality and legal considerations. Each foundation helps create an environment where people with disabilities can participate equally in society. To achieve true inclusion, all sectors (education, health, employment and social services) need to work together to eliminate barriers, raise awareness and ensure that everyone has access to services. A community that is inclusive and accessible is one that values diversity and strives for equality for all its members.

“Disability: Inclusion and Accessibility”

by Varsha Kaushik MBA (A), USMS GGSIPU.

Disability inclusions and accessibility are crucial aspects of creating equitable environment in education workplaces and broader society. Embracing these principles involves addressing various themes such as inclusive teaching and learning support services, social inclusions, culture, well-being intersectionality, diversity and legal and policy considerations.

Inclusive teaching and learning support services:

Inclusive teaching practices involve adapting educational materials and methods to accommodate diverse learning needs. Schools and educational institutions should develop individualized learning plans that address the specific needs of students with disabilities. Teachers and academic staff require training on disability awareness and inclusive teaching strategies.

Social Inclusions and Culture:

Accessibility is not limited to physical spaces but extends to digital environments and social interactions. Building an inclusive culture involves challenging stereotypes, combating ableism and creating spaces where everyone feels valued and respected. Encourage the active participation of individuals with disabilities in all areas of society from community events of decision-making processes.

Well-being and Intersectionality:

Ensuring the well-being of individual and disabilities involves addressing their disabilities involves addressing their physical, emotional, and mental health needs. Recognize that disability intersects with other aspects of identity such as race, gender and socio-economic status.

Legal and policy considerations:

Adhering to laws and regulations related to disability rights is fundamental. This includes the American with disabilities act in United states, the equality act in the UK and similar legislation worldwide. These laws mandate accessibility, anti-discrimination measures, and reasonable accommodations policies and procedures should be regularly reviewed and updated to reflect changes in legislation and best practices. Institutions must stay informed about evolving standards and adapt their approaches to meet current needs.

Conclusion:

Hence, Disability inclusions and accessibility are multifaced issues that require comprehensive approaches by focusing on inclusive teaching and learning social inclusion and culture well-being intersectionality and legal considerations, we can build more equitable environments that respect and support individuals with disability through ongoing commitment and collaborations. Society can work towards the inclusion and accessibility for all.

AWARENESS GENERATION BY UIAC
Spinal Muscular Atrophy (SMA)
Awareness Month 2024



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SPINAL MUSCULAR ATROPHY
(SMA)
AWARENESS MONTH 2024



August

Spinal muscular atrophy (SMA) is a progressive neurodegenerative disease that affects the motor nerve cells in the spinal cord and impacts the muscles used for activities such as breathing, eating, crawling, and walking.

Here we respect and support Disability Inclusion!

1



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What is SMA?

Spinal muscular atrophy (SMA) is a genetic disorder caused by defective copies of SMN1 gene. The disease affects the nerve cells of the spinal cord. The damage to the nerve cells leads to weakness of muscles of all limbs and trunk of the body.

It is one of the rare disorders where new treatment options are changing the paradigm of outcome. Most of the cases of SMA are due to defect in the both copies of SMN1 gene in the patient and cause death during infancy or lifelong disability. The novel treatments have shown opportunity of improving longevity and quality of life for patients with SMN1 related SMA.

Source: Ministry of Health and Family Welfare (MoHFW), Government of India.



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Spinal Muscular Atrophy (SMA)

What You Need to Know

- Spinal muscular atrophy (SMA) is a disorder affecting the motor neurons—nerve cells that control voluntary muscle movement. These cells are located in the spinal cord.
- Because the muscles cannot respond to signals from the nerves, they atrophy — weaken and shrink — from inactivity.
- One in every 6,000 babies is born with SMA. It is one of the most prevalent genetic disorders affecting young children and a major cause of death in infancy.
- SMA can strike children at any age. SMA in infancy and early childhood is associated with worse outcomes, while patients who develop symptoms later in childhood or in adolescence usually have a more positive prognosis.
- SMA does not affect sensory nerves or intellect, but it has been observed that many patients with SMA are highly intelligent.

Source: <https://www.hopkinsmedicine.org/health/conditions-and-diseases/spinal-muscular-atrophy-sma#:~:text=What%20You%20Need%20to%20Know,weaken%20and%20shrink%20%E2%80%94%20from%20inactivity.>



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What are the types of SMA?

Depending on the severity the disease is classified into main 4 types. SMA type I manifest before 6 months of age with floppiness and weakness leading to lack of limb movements and death before two years due to respiratory failure without treatment. The children manifesting between 6 month to 2 years of life, grouped as SMA type II, are able to sit on their own but are wheel chair bound and usually develop spinal deformities after teenage. Some cases manifesting during later childhood and adulthood may remain mobile for long time.

How is SMA inherited?

In patients with SMA, both the copies of the SMN1 gene are defective, one defective copy inherited from the parents. It means that the parents are carriers of the disease and have one normal and one defective copy of SMN1 gene. There can be more than one affected offspring in a family. Frequency of SMN1 mutation carriers in Indian population is reported to be around 3%.

Source: Ministry of Health and Family Welfare (MoHFW), Government of India.



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SMA Signs and Symptoms

- Spinal muscle atrophy symptoms vary, and may be mild or disabling, but involve a weakness of the muscles that control movement. Involuntary muscles, such as those in the heart, blood vessels and digestive tract, are not affected.
- SMA weakens the muscles closest to the center of the body, including the shoulders, hips, thighs and upper back. The affected child may develop a curve in the spine (scoliosis) due to loss of size and strength of the back muscles.
- Progression of SMA can also affect breathing and swallowing, which can threaten the life of the patient.

Source: <https://www.hopkinsmedicine.org/health/conditions-and-diseases/spinal-muscular-atrophy-sma#:~:text=What%20You%20Need%20to%20Know,weaken%20and%20shrink%20%E2%80%94%20from%20inactivity.>



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Govt of India: Supporting SMA

Read at:

**Ministry of Health and Family Welfare (MoHFW),
Government of India.**

<https://rarediseases.mohfw.gov.in/Documents>

Spinal muscular atrophy (SMA)

[https://rarediseases.mohfw.gov.in/uploads/Content/1627981400 Spinal Muscular Atrophy.pdf](https://rarediseases.mohfw.gov.in/uploads/Content/1627981400%20Spinal%20Muscular%20Atrophy.pdf)

Government of India has identified 12 institutions which are actively managing patients suffering from rare diseases. These institutes have been designated as Centres of Excellence(CoE).

[https://rarediseases.mohfw.gov.in/Hospital Treating Rare Diseases](https://rarediseases.mohfw.gov.in/Hospital_Treating_Rare_Diseases)



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Where can I find more information about spinal muscular atrophy?

Information may be available from the following
organizations and resources:

Ministry of Health and Family Welfare (MoHFW),
Government of India.

Cure SMA

Genetic and Rare Diseases (GARD) Information Center
Muscular Dystrophy Association

Spinal Muscular Atrophy Foundation

Disclaimer:

This information is provided solely for awareness generation and has been obtained
from publicly available open sources.

Let's Test Your Disability Inclusion Quotient (DIQ)

1. Which of the following is considered a disability under the Rights of Persons with Disabilities Act, 2016 in India?

- a) Anxiety
- b) Cancer
- c) Intellectual disability
- d) Common cold

2. What does "reasonable accommodation" mean in the context of disability inclusion?

- a) Providing free accommodation to persons with disabilities
- b) Modifying the work environment to suit all employees
- c) Necessary and appropriate modification without imposing a disproportionate burden
- d) Lowering performance expectations for persons with disabilities

3. Which of the following is NOT a key principle of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)?

- a) Full and effective participation and inclusion in society
- b) Equality between men and women
- c) Recognition of sign language as an official language
- d) Respect for inherent dignity

4. In which year was the UNCRPD adopted?

- a) 1992
- b) 2006
- c) 1989
- d) 2000

5. What is the focus of Universal Design in the context of accessibility?

- a) Creating special devices for persons with disabilities
- b) Designing products, environments, and services to be usable by all people
- c) Building separate infrastructure for disabled users
- d) Developing luxury amenities for inclusive communities

6. What percentage of the global population is estimated to live with some form of disability?

- a) 5%
- b) 10%

- c) 15%
- d) 20%

7. Which of the following is a barrier to accessibility for persons with disabilities?

- a) Inclusive policies
- b) Physical barriers such as stairs without ramps
- c) Equal pay initiatives
- d) Disability-awareness training for all employees

8. Indian Sign Language (ISL) is officially recognized by which Indian institution?

- a) National Institute of Speech and Hearing
- b) Indian Sign Language Research and Training Centre (ISLRTC)
- c) Rehabilitation Council of India (RCI)
- d) All India Institute of Medical Sciences (AIIMS)

9. The term "assistive technology" refers to:

- a) Devices and services that improve the functional capabilities of persons with disabilities
- b) Gadgets used by healthcare professionals only
- c) Special telephones for people who are visually impaired
- d) None of the above

10. Which of the following is an example of an invisible or hidden disability?

- a) Blindness
- b) Hearing loss
- c) Autism Spectrum Disorder (ASD)
- d) Wheelchair use

11. What is the purpose of a Disability Equality Index (DEI)?

- a) To measure the level of disabilities in a community
- b) To evaluate the inclusion practices of organizations
- c) To classify different types of disabilities
- d) To monitor government disability programs

12. The primary goal of inclusive education is:

- a) To provide special education services in separate schools
- b) To ensure that all students, regardless of ability, can learn together
- c) To focus on high-achieving students with disabilities
- d) To segregate students with different learning needs

13. Which organization works specifically to promote accessibility and inclusion for persons with disabilities worldwide?

- a) International Monetary Fund (IMF)
- b) International Disability Alliance (IDA)
- c) World Economic Forum (WEF)
- d) UNESCO

14. A sign language interpreter is primarily used for:

- a) Translating spoken language to written text
- b) Translating spoken language into sign language for people who are deaf or hard of hearing
- c) Assisting persons with mobility disabilities
- d) All of the above

15. The term "inclusion" in the context of disability refers to:

- a) Placing all individuals in separate groups according to their disabilities
- b) Ensuring equal opportunities for participation and removing barriers
- c) Creating exclusive services for persons with disabilities
- d) Implementing token gestures for inclusion

16. What does the acronym RCI stand for in the context of disability in India?

- a) Rehabilitation Council of India
- b) Regional Council for Inclusion
- c) Rights for Citizens with Impairments
- d) Research Council for Innovation

17. Which of the following is a legal obligation under the Rights of Persons with Disabilities Act (RPwD) in India?

- a) Free education for all persons with disabilities
- b) Accessibility in public buildings, transportation, and services
- c) Providing employment quotas for persons with disabilities
- d) Creating separate workspaces for persons with disabilities

18. Which of these can help create a more inclusive workplace for persons with disabilities?

- a) Providing disability etiquette training for employees
- b) Creating segregated workstations for persons with disabilities
- c) Reducing working hours for all disabled employees
- d) Avoiding hiring people with disabilities to avoid extra costs

19. What is an example of a social model of disability?

- a) Disability is caused by an individual's physical impairment
- b) Disability is the result of an inaccessible environment or attitudes
- c) Disability is a medical condition that needs to be cured
- d) Disability only affects people in low-income countries

20. Which of the following is a key feature of accessible communication for persons with

disabilities?

- a) Providing information only in large print
 - b) Using multiple formats, such as Braille, sign language, and captioning
 - c) Communicating only through written text
 - d) Avoiding the use of technology in communication
-

Answer Key:

- 1. c) Intellectual disability
- 2. c) Necessary and appropriate modification without imposing a disproportionate burden
- 3. c) Recognition of sign language as an official language
- 4. b) 2006
- 5. b) Designing products, environments, and services to be usable by all people
- 6. c) 15%
- 7. b) Physical barriers such as stairs without ramps
- 8. b) Indian Sign Language Research and Training Centre (ISLRTC)
- 9. a) Devices and services that improve the functional capabilities of persons with disabilities
- 10. c) Autism Spectrum Disorder (ASD)
- 11. b) To evaluate the inclusion practices of organizations
- 12. b) To ensure that all students, regardless of ability, can learn together
- 13. b) International Disability Alliance (IDA)
- 14. b) Translating spoken language into sign language for people who are deaf or hard of hearing
- 15. b) Ensuring equal opportunities for participation and removing barriers
- 16. a) Rehabilitation Council of India
- 17. b) Accessibility in public buildings, transportation, and services
- 18. a) Providing disability etiquette training for employees
- 19. b) Disability is the result of an inaccessible environment or attitudes
- 20. b) Using multiple formats, such as Braille, sign language, and captioning

Updates and News from The World of Disability Inclusion



Indian Sign Language Research and Training Centre

Department of Empowerment of Persons with Disabilities (Divyangjan)

Ministry of Social Justice & Empowerment, Government of India

To commence Employability Skills for PwDs course Under the PM DAKSH – NATIONAL ACTION PLAN, for Skill Development of PwDs

Name of the course	Employability Skills for PwDs course
Qualification	Ability to read and write
Minimum and Maximum Age	15 – 59 years
candidates	Hearing Impaired
Duration	70 Hours (10 days - 20 days)
Course fee	Nil
Course commencement date	10/8/2024
Mode of Teaching	Through Sign Language

Application should be made on plain paper giving the following details: Name of the candidate, UDID number, Gender, Aadhaar Number, Qualification, State, District, Mobile number, Date of Birth and bank details.

Documents required: UDID Card, Aadhaar card, Bank Account passbook Xerox.

Scan the filled in application along with the above mentioned documents and email to skilltrainingislrtc@gmail.com before 9/08/24.

Module no. 403-406, Fourth Floor, NSIC Business Park, Okhla Industrial Estate, New Delhi - 110020

<http://islrtc.nic.in/>

islrtcnewdelhi@gmail.com

[@islrtc](https://twitter.com/islrtc)

[@islrtc](https://www.facebook.com/islrtc)

[ISLRTC NEW DELHI](https://www.youtube.com/channel/UCISLRTCNEWDELHI)



Figure 1: The helpline is an initiative by the Ministry of Social Justice and Empowerment, Government of India.



Figure 2: The Department of Empowerment of Persons with Disabilities offers a National Overseas Scholarship for PwD students.



Figure 3: National Awards 2024, organized by the Ministry of Social Justice and Empowerment, Government of India.



Figure 4: Swachhta Pakhwara, an initiative by the Ministry of Social Justice and Empowerment, Government of India



Figure 5: President Droupadi Murmu presents Padma Shri in the field of Social Work to Dr. K. S. Rajanna. He is known for his work for the welfare of Divyangjan. Despite having lost his hands and feet in childhood, he has made spectacular achievements.

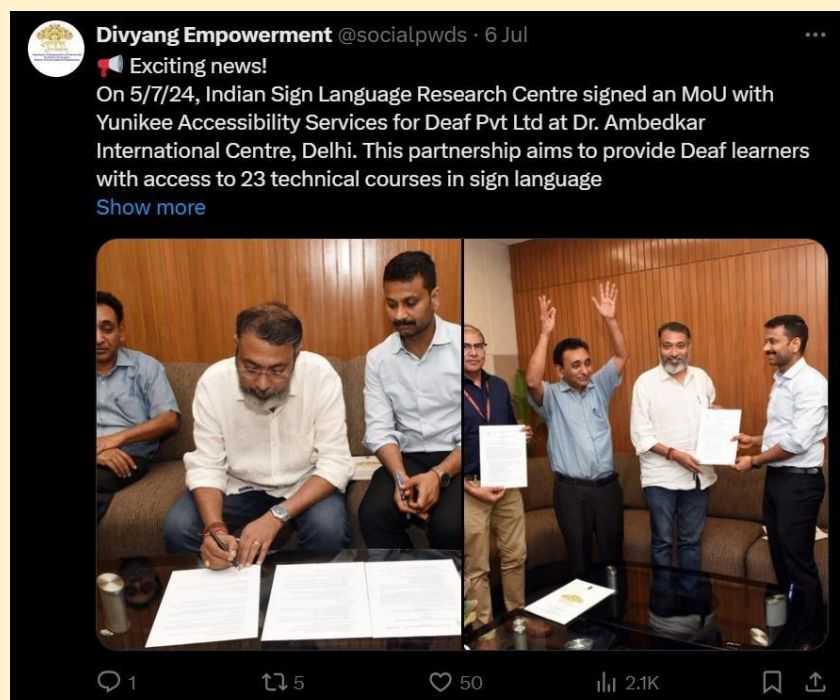


Figure 6: Indian Sign Language Research Centre signed an MoU with Yunikey Accessibility Services for Deaf Pvt Ltd at Dr. Ambedkar International Centre, Delhi

OUR TEAM

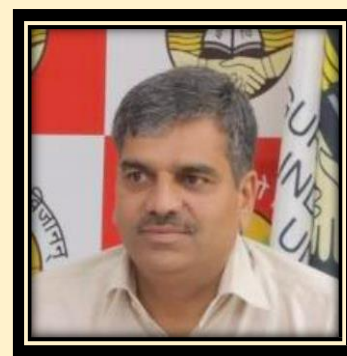
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HOW CAN YOU CONTRIBUTE.....

VOLUME 10

**Soon we will announce the call for contribution
for**

Volume 10

STAY TUNED!

You can contribute in the form of:

- **Giving ideas on how you can help PwDs**
- **Articles**
- **Puzzles**
- **News Items etc...**

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