

Introduction:

The Purple Fest, organized by the Office of the State Commissioner for Persons with Disabilities in collaboration with the Directorate of Social Welfare and the Entertainment Society of Goa, took place from January 8th to 13th, 2024. This groundbreaking event marked India's first-of-its-kind inclusive festival, dedicated to embracing, expressing, and celebrating persons with disabilities. The festival aimed to showcase the possibilities of creating a welcoming and inclusive world for everyone.

The International Purple Fest in Goa was inaugurated by Chief Minister Pramod Sawant, Union Minister Ramdas Athavale, MP Sadanand Tanavade, Social Welfare Minister Subhash Phal Dessai, Sports Minister Govind Gaude, and other dignitaries.



Participation Experience:

As an attendee from January 8th to 10th, the festival provided an enriching and inspiring experience. Beyond being a platform for persons with disabilities to showcase their talents, it fostered an environment of understanding and acceptance.

Day 1 (8 Jan) - Purple Exhibition:

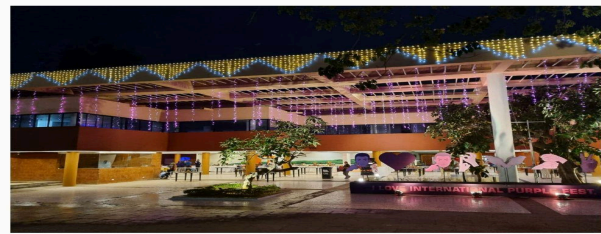
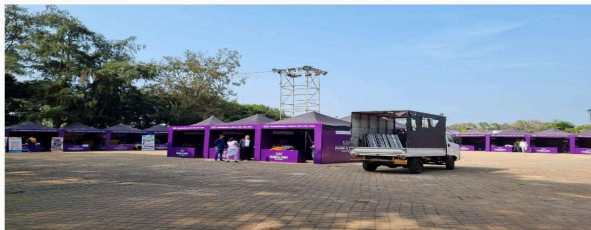


Day 1 at the International Purple Fest proved to be an enlightening experience, as I delved into the vibrant Purple Exhibition Pavilion. The pavilion housed numerous stalls from diverse organizations, encompassing both government and non-government entities. My focus gravitated toward those dedicated to addressing intellectual and developmental disabilities (IDD). Amidst the array of stalls, I discovered noteworthy

contributions from organizations like the Ali Yavar Jung National Institute and its regional centers, Pratham, Astha, Nayi Disha, Sangath, Sethu, NIMHANS, RCI, Amazon, SBI, NIPiED, Keystone Institute India and Sensory All.



These centers are actively engaged in empowering caregivers and children with IDD. Their initiatives range from developing comprehensive teaching and learning modules to creating parent training programs and teaching children with IDD. During my exploration, I seized the opportunity to procure essential modules from these stalls, each offering valuable insights and resources.



Notably, I established contact for potential future collaborations and communication. The commitment of these organizations to the empowerment of individuals with IDD and their caregivers is commendable, and I look forward to further engagement and collaboration in the days to come.



Day 2&3 (9 - 10 Jan) - Purple Convention :

Days 2 and 3 at the International Purple Fest were marked by my active participation in a groundbreaking national conference on invisible disabilities. This pioneering event was organized by Chronic Pain India in collaboration with the Purple Fest, the Government of Goa, Swablamban - Department of Empowerment of Persons with Disabilities, the Ministry of Social Justice & Empowerment, and the State Commission for Persons with Disabilities. Notably, this conference stood out as the first of its kind dedicated exclusively to the discussion of invisible disabilities.

The distinguished inauguration ceremony was graced by Shri. Subhash Phal Dessai, the Social Welfare Minister of Goa, and Shri. Guruprasad Pawaskar, Commissioner of the Office of the State Commission for Persons with Disabilities. Their presence underscored the significance of the conference and highlighted the commitment of the government to addressing the issues surrounding invisible disabilities. Overall, the conference served as a platform for meaningful discussions, fostering awareness, understanding, and empathy towards individuals with invisible disabilities.

Invisible Disabilities:

Invisible disabilities refer to health conditions that are not immediately apparent or visible to others, yet they significantly impact an individual's daily life and functioning. Unlike visible disabilities, which may manifest as physical impairments or

noticeable differences, invisible disabilities are often characterized by symptoms that are not easily observable.

Examples of invisible disabilities include Chronic Pain, Mental Disabilities, or Illnesses, such as Depression, Anxiety, Addiction, ADHD, Dyslexia, Autism, Schizophrenia, Autoimmune Disorders, Cognitive Impairments, and certain Neurological Conditions. These are classified as invisible disabilities because they are usually not detected immediately by looking or talking to a person. Individuals with invisible disabilities may face unique challenges as their conditions are not always understood or recognized by others.

One of the key aspects of invisible disabilities is the potential for misunderstanding or skepticism from others, as the absence of visible cues can lead to misconceptions about the severity or legitimacy of the condition. This lack of visibility can contribute to difficulties in obtaining support, accommodations, or empathy from both society and sometimes even within personal relationships.

Conference Sessions Overview:

The conference comprised a total of six sessions, each delving into different aspects of invisible disabilities and their implications on individuals and society. The panelists, hailing from various parts of India, brought diverse perspectives and expertise to the table. What set this conference apart was the inclusion of panelists who were themselves living with invisible disabilities. Their narratives provided invaluable insights into the practical challenges and experiences associated with these conditions.

Embarking on a profound exploration of Invisible Disabilities, The session commenced with an impactful introduction and an accompanying video that set the stage for an enlightening journey.



Session-I: Journey to Diagnosis and Treatment - The challenges and time period a person faces to get diagnosed and treated.

Under the adept moderation of Dr. Anubha Mahajan and Anjali Vyas, Session I unfolded as a profound exploration into the personal journeys of individuals grappling with invisible disabilities. Smitha Sadasivan, a resilient panelist, shared her poignant experiences, illuminating the hurdles faced during diagnosis and treatment. Her candid reflections delved into the

struggles of being misunderstood by professionals and the complexities encountered while seeking accommodations.

Joining the discourse, Dr. Nikhil Gupta, a seasoned Dermatologist, and Subhojit Goswami, a senior Program Manager at The Leprosy Mission Trust India, added depth to the conversation. Dr. Gupta shared valuable insights on the pivotal role of medical practitioners in reshaping the narratives surrounding invisible disabilities. Advocating for enhanced training, he emphasized the necessity of rotational duties to provide professionals with hands-on experience in diverse departments.

Subhojit Goswami brought a unique perspective, highlighting the crucial need for advocacy at both policy and community levels. His reflections underscored the transformative impact that changes in policy narratives can bring to the rehabilitation of individuals with invisible disabilities. The panelists collectively addressed the existing disconnect between the 21 disabilities enumerated in the Rights of Persons with Disabilities (RPWD) Act and the nuanced nature of conditions like Chronic Pain, Mental Disabilities, and Neurological Conditions.

A recurring theme throughout the session was the call for heightened awareness among policymakers regarding invisible disabilities. The panelists emphasized the imperative for policymakers to deepen their understanding, bridging the gap between legislation and the intricate realities of these conditions. This deeper awareness, they argued, would pave the way for accurate recognition, timely diagnosis, and effective treatment, contributing to the comprehensive development of support

systems for individuals navigating the challenges of invisible disabilities.

Session-II: Certification and Health Insurance Crisis - To highlight the exclusion criteria with minimal rights and insufficient healthcare provided to a person with a invisible disability.

Session-II of this discussion series delves into the often-overlooked challenges faced by individuals with invisible disabilities in obtaining certifications and adequate health insurance.

Under the adept moderation of Aarti Batra , facilitated an insightful conversation with panelists Muraleedharan Vishwanath, Ayushmita, and Sameer Sethi. Each panelist brought forth their experiences and perspectives, shedding light on the existing gaps and hurdles in the certification and insurance processes.

Key Points Discussed:

Progressive Policies with Lingering Gaps:

The panelists acknowledged the existence of progressive policies addressing disability rights; however, they emphasized the persisting gaps within these policies. Despite advancements like the Rights of Persons with Disabilities Act (RPWD) 2016, there are still notable exclusions and limitations in the certification and insurance landscape.

Clarity Amidst Clauses:

The discussion brought attention to the complexity of insurance policies, filled with numerous clauses that often hinder the

seamless access to certifications and insurance for individuals with invisible disabilities. The need for clearer, more accessible information was highlighted as a crucial aspect for the community.

Pros and Cons Analysis:

Muraleedharan Vishwanath, Ayushmita, and Sameer Sethi shared their personal insights, conducting a thorough analysis of the pros and cons associated with the existing disability-related laws and policies. This scrutiny aimed to identify areas for improvement and refinement.

Challenges Stemming from Limited Awareness:

A recurring theme in the discussion was the challenge posed by insufficient awareness among professionals and the general public. The panelists stressed the importance of heightened awareness to ensure a smoother certification and insurance process for individuals with invisible disabilities.

RPWD 2016: A Foundation with Room for Growth:

While acknowledging the significance of the RPWD 2016, the panelists discussed the need for continuous improvement and expansion. The existing conditions listed in the act may not encompass the entirety of invisible disabilities, necessitating ongoing revisions to better cater to the diverse needs of the community.

Session-III: Gender, Mental Health & Invisible Disability - The intersectionality of mind and body when a person is living with any kind of chronic illness and the psychosocial impact towards it.

Examine how societal stigmas related to gender and mental health can compound the challenges faced by individuals with invisible disabilities.

In Session-III, a profound discussion unfolded on the intricate web of challenges faced by individuals grappling with the intersectionality of gender, mental health, and invisible disabilities. The panel featured distinguished speakers Srinidhi Raghavan, Joshua Mark George, Praful Baweja, and Abhishek Annica, guided by the insightful moderation of Kavya Mukhija. Together, they delved into the nuanced experiences and compounded difficulties arising from complex invisible disabilities, shedding light on the intersections with mental health, gender, and other societal factors.

Key Points Discussed:

Complex Nature of Invisible Disabilities:

The panelists articulated the intricate nature of invisible disabilities, emphasizing the multifaceted challenges individuals face when dealing with chronic illnesses that impact both the mind and body.

Intersectionality in Focus:

Kavya Mukhija and the panel drew attention to the layers of intersectionality, considering preexisting mental health conditions, gender, and caste, among other factors. This comprehensive approach aimed to capture the full spectrum of challenges faced by individuals with invisible disabilities.

Living with Complexity:

The discussion explored the lived experiences of individuals navigating complex invisible disabilities in conjunction with other intersectionalities. The panelists shared personal stories, highlighting the difficulties and resilience required to navigate such intricate challenges.

Session-IV: The journey from Education to livelihood while Living with an invisible disability No certificate, no rights yet trying to earn the daily bread and medicines

Dr. Anubha Mahajan skillfully led Session IV, delving into the intricate journey from education to livelihood for those living with invisible disabilities. The panel, featuring Alice Abraham, Shanti Raghavan, and Radhika Alkazi, provided profound insights into the profound impact of invisible disabilities on their educational and professional trajectories.

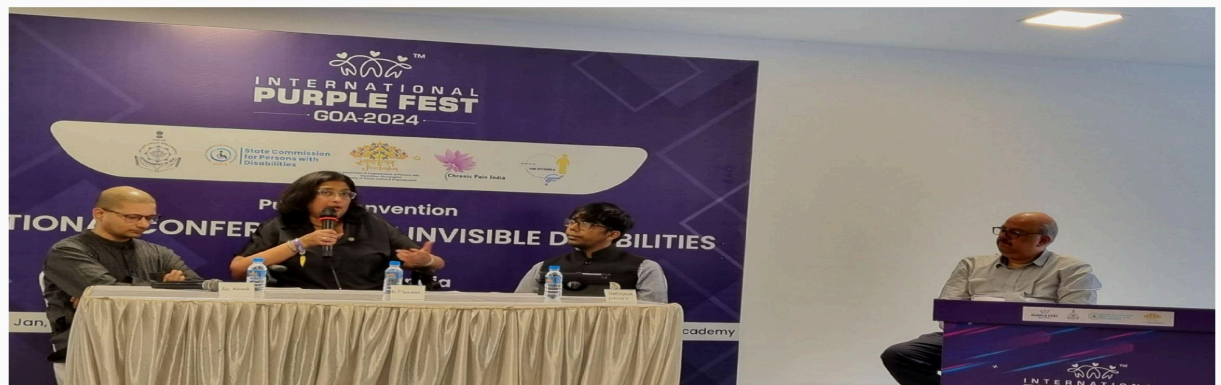
The panelists candidly shared their personal experiences, shedding light on the day-to-day challenges encountered in both education and employment. They highlighted the less inclusive environments that often contribute to high dropout rates among individuals with invisible disabilities. The discussion illuminated the struggles faced by individuals striving to balance the demands of academia and the workplace with their unique conditions.

Alice Abraham, Shanti Raghavan, and Radhika Alkazi collectively addressed the need for increased understanding of invisible disabilities among educational institutions and employers. They emphasized the importance of providing accommodations tailored to the specific needs of individuals with invisible disabilities, noting

that such adjustments could significantly reduce dropout rates. The panelists underscored the positive impact that a more inclusive environment could have on the educational and professional journeys of individuals living with invisible disabilities.

In conclusion, Session IV served as a platform for constructive dialogue on the challenges faced by individuals with invisible disabilities in their pursuit of education and livelihood. The panelists' personal narratives and proposed solutions underscored the significance of creating supportive and accommodating environments, ultimately contributing to the broader goal of inclusivity and equal opportunities for all.

Session-V: Climate Change, Disaster Management & Invisible Disability - The rise of symptoms and challenges that are increasing with adverse global climatic phenomena.



Session V of the International Purple Fest continued the profound exploration, addressing the critical issue of climate change and disaster management's impact on individuals with invisible disabilities. Moderated by Shashank Pandey and featuring speakers Adv Abhishek Kumar, Meenakshi Venkatraman, and Dr. Mohammed Asheel, the panel delved into the pressing concerns of the global community.

The speakers drew attention to the overarching issue of climate change, emphasizing how the unpredictability of weather patterns, including heatwaves, cold waves, and rain, affects everyone. However, they underscored a critical point - individuals with invisible disabilities are more vulnerable and significantly impacted by these environmental changes. The discussion went beyond mere observation of weather systems to address the specific challenges faced by those with invisible disabilities.

Adv Abhishek Kumar, Meenakshi Venkatraman, and Dr. Mohammed Asheel collectively highlighted the heightened vulnerability of individuals with invisible disabilities to various natural disasters such as earthquakes, floods, heat waves, and cold waves. The panelists emphasized that these vulnerable groups often face more severe consequences due to their unique needs and challenges.

The session served as a wake-up call, prompting a call to action to address the intersectionality of climate change and invisible disabilities. The speakers advocated for inclusive disaster management strategies that consider the specific needs of individuals with invisible disabilities. Session V captures the urgency of recognizing and mitigating the impact of climate

change on this vulnerable demographic, thereby contributing to a more equitable and inclusive approach to disaster preparedness and response.

Session-VI: The Unseen Reality of Caregiving - Horrors of low knowledge around diseases leading to low awareness, uncertainty, and understanding among caregivers.

Moderated by Anjali Vyas, Session VI at the International Purple Fest brought forth a poignant exploration into the often-overlooked realm of caregiving. The panel, comprising Renuka Malekar, Bhavna Issar, Pratik Aggarwal, and Reena Mukhija, shared their heartfelt journeys as caregivers, offering profound insights into the multifaceted challenges inherent in this role.

Each speaker, having experienced caregiving firsthand, illuminated the emotional, physical, and financial complexities that caregivers navigate on their journey. They candidly expressed the struggles encountered in the transition from awareness to acceptance, emphasizing the difficulty of making decisions that ensure the best possible care for their loved ones.

The narratives painted a vivid picture of the diverse roles a caregiver assumes - from providing emotional support to managing the practical aspects of healthcare and finances. The speakers highlighted the inherent difficulties of balancing these roles, underscoring the need for a holistic approach to caregiving that addresses the comprehensive well-being of both caregivers and their loved ones.

Throughout the session, a common thread emerged - hope as the key element in the caregiving journey. The speakers emphasized the importance of maintaining hope, as it becomes a driving force that sustains caregivers through the challenges they face. The Session VI encapsulates the profound stories shared by the panelists, shedding light on the often unseen reality of caregiving and recognizing the invaluable role that hope plays in this vital aspect of support for individuals with disabilities.

Summary:

The International Purple Fest, held in Goa from January 8th to 13th, 2024, marked a historic milestone as the first inclusive festival in India dedicated to persons with disabilities. Inaugurated by Chief Minister Pramod Sawant and Union Minister Ramdas Athavale, the festival aimed to create a welcoming and inclusive world for all.

As an attendee from January 8th to 10th, the experience proved to be enriching and inspiring. Day 1 featured the Purple Exhibition Pavilion, hosting diverse stalls from organizations addressing

intellectual and developmental disabilities (IDD). Notable contributors included the Ali Yavar Jung National Institute, Pratham, and Amazon, actively empowering caregivers and children with IDD. The day provided valuable insights, resources, and potential collaboration opportunities.

Days 2 and 3 centered around the Purple Convention, a groundbreaking national conference on invisible disabilities organized by Chronic Pain India in collaboration with various entities. This conference, the first of its kind, delved into health

conditions like Chronic Pain, Mental Disabilities, and Neurological Conditions that aren't immediately visible. It emphasized the challenges faced by individuals with invisible disabilities, fostering awareness and understanding.

The conference comprised six sessions covering crucial aspects. Session I explored the challenges of diagnosis and treatment, featuring insights from individuals living with invisible disabilities. Session II focused on the certification and health insurance crisis, shedding light on existing gaps and hurdles. Session III addressed the intersectionality of gender, mental health, and invisible disabilities, recognizing the complex nature of these conditions.

Session IV, guided by Dr. Anubha Mahajan, discussed the journey from education to livelihood for individuals with invisible disabilities. Panelists shared personal experiences, emphasizing the need for increased understanding and inclusive environments to reduce dropout rates.

Session V highlighted the impact of climate change and disaster management on individuals with invisible disabilities. The session served as a call to action for inclusive disaster management strategies considering the unique needs of this vulnerable demographic.

Session VI, moderated by Anjali Vyas, explored the unseen reality of caregiving. Caregivers Renuka Malekar, Bhavna Issar, Pratik Aggarwal, and Reena Mukhija shared heartfelt journeys, emphasizing the multifaceted challenges and the key role of hope in caregiving.

The Closing Ceremony reflected on the profound discussions, acknowledging the various facets of living with invisible disabilities. Overall, the International Purple Fest successfully promoted inclusivity, understanding, and celebrated the talents of persons with disabilities, setting a precedent for future inclusive events.



