INTERNATIONAL PURPLE FEST
GOA-2024

Purple People

RISING FLAME
Purple People was conceptualised and organised by Rising Flame as a key partner of International Purple Fest 2024.


Most importantly we thank all the speakers and moderators who made Purple People rich with their valuable and honest insights and work. We admire their journey, and courage with which they navigate the world with their disability experiences.

• Abhishek Anicca (Writer)  
• Aditi Gangrade (Much Much Media)  
• Aishwarya Othena (Research scholar)  
• Anubha Singhal (Enable Me Access Association)  
• Apoorv Kulkarni (OMI Foundation)  
• Antara Telang (Gnothi Seauton)  
• Barsha Banerjee (Perkins India)  
• Dr. Shikha Silliman Bhattacharjee (Lawyer and Researcher)  
• Dipti Prasad (nobaflx)  
• Jo Chopra McGowan (Latika)  
• Kanchan Pamnani (Advocate and Solicitor)  
• Malini Chib (Writer)  
• Nandita DeSouza (Sethu Centre for Child Development)  
• Nidhi Ashok Goyal (Rising Flame)  
• Pavan Kumar Muntha (Swaadikar)  
• Prachi Arora (Indian Sign Language Interpreter and CODA)  
• Pranav Sethi (GeoHazards Society)  
• Prasad Joshi (Goa Association of the Deaf)  
• Preetam Sunkavalli (Mahindra Group)  
• Raj Mariwala (Mariwala Health Initiative)  
• Sabina D’Cunha (Hemophilia Society Panjim Chapter Women’s group)  
• Sandhya Menon (Communications professional)  
• Shivangi Agrawal (Disability and Queer Rights Activist)  
• Shruti Naithani (Sense International India)  
• Soumita Basu (Zyenika Inclusive Fashion)  
• Srinidhi Raghavan (Rising Flame)  
• Surashree Rahan (Yearbook Canvas)  
• Sweta Mantrii (Stand-Up Comic)  
• Vineet Saraivala (Atypical Advantage)  
• Virali Modi (Writer, Motivational speaker)
INTRODUCTION FOR PURPLE PEOPLE

For years, people with disabilities’ first and primary ask has been to see them as people first. People with disabilities are often not considered as full human beings, with lives and dreams, with hopes and desires. They are routinely ungendered, stripped of their human identity, and desexualised in order to reduce them to their disability.

Within persons with disabilities, women and gender marginalised persons with disabilities face unique barriers while navigating the world. As a result of which, often their lived experiences do not make it to the public eye. They face gender stereotypes, unequal access to opportunities, limited decision-making power, and societal expectations that restrict their roles and choices.

To address these challenges and bring the often-unacknowledged conversations to the front and centre, Rising Flame conceptualised and curated the first-ever, unique gender track at the international Purple Fest called Purple People, from January 11 to 13, 2024 at Kala Academy Goa to spotlight the challenges faced by women, gender-marginalised persons and all people with disabilities, and their specific life experiences. Under Purple People, we organised panels, masterclasses, and a reading session covering work and leadership, accessibility, mobility, technology, sexuality, disabled parenting, climate change, consent, and more.

This booklet aims to capture the diverse conversations that took place then and bring it all together. These illustrations and pieces will challenge stigma to show women and persons with disabilities as full human beings with lives and careers, with ambition and love, as parents and caregivers.
Challenge your own ideas!
What does productivity mean?
What does leadership look like?
What does a leader look like?

"If you don't say 'Entrepreneur with Diabetes', why am I called on 'Entrepreneur with disability'?"

I am an ENTREPRENEUR. Period.

→ Pressure to represent community, not let them down.
→ Creating an inclusive and diverse work environment that is feminist and holds space for care.

"I come from an empowered and supportive family. Multiple people in my family are disabled, and they are all high achievers. I thought the world was a fair place. It's only when I went to college did I realise it wasn't."

Am I living for myself, or for the ableist society?

→ Fixed ideas about how a male leader shows up, pressure to be aggressive.
→ The push is for a dignified income, that's all we ask.
→ Tendency to gloss over struggles, not ask for accommodations, or for what one needs.
→ Constantly trying to meet able-bodied standards for achievement and productivity.

"When you are a person with a disability, we try to appeal to what the society wants us to be, and trying to prove a point constantly."

The capabilities of disabled people are doubted.

→ There is a deficit narrative around us which focuses on what we can't do
→ BIAS: Senior and mid level leadership roles not normally given to people with disabilities.

"The tag of overachiever gets attached to us. Whatever I do gets called an achievement. At this point, sometimes I live wondering what I need to achieve next, instead of just living my life."

Facing DOUBT CONSTANTLY

→ Invisible disabilities not acknowledged.
→ Constantly having to prove disability. "You don't look autistic."
→ "Are you really not feeling okay or are you pretending to avoid me?" Disability doesn't look the same hour-to-hour, day-to-day, which doesn't fit into how the ableist world views disability.

"There are good days and bad days. Fluidity is important to acknowledge. Most people are uncomfortable with anything that doesn't fit into their narrative of disability."

"I work 16 hours a day and I can assure you, your health will go away but the guilt won't go away. There is always a nagging doubt: Could I have done more?"

If there are more disabled people, women and LGBTQIA+ people behind cameras, there would be greater diversity and inclusion ON camera.

"The neurotypical ways of working weren't working for me, so I tried to create an inclusive and diverse workspace."

"I work 16 hours a day and I can assure you, your health will go away but the guilt won't go away. There is always a nagging doubt: Could I have done more?"
Panaji: “I have many physical problems but it is never [seen as] Soumita is having a problem, it is always an entrepreneur with disability is having a problem, it is an entrepreneur working in the field of disability,” said Soumita Basu, the founder and CEO of Zyenika Inclusive Fashion during a panel discussion on ‘Gender, leadership and the world of work’ at the International Purple Fest Goa 2024 on January 11, 2024 at Purple People organised by Rising Flame.

The panel was moderated by Nidhi Goyal, Founder and Executive Director of Rising Flame with the speakers-Aditi Gangrade, Co-Founder of Much Much Media, Vineet Saraiwala, Founder of Atypical Advantage, Surashree Rahane, Founder and CEO of Yearbook Canvas and Soumita who addressed the multitudes of challenges they face as entrepreneurs living with disabilities, from the stigma and the constant pressure to overperform to struggles with acquiring investments and asking for accommodations.

As a person with disability, one is always trying to prove the society wrong, said Vineet, “If they say, I can’t run because I am blind, I want to do it just to prove a point to the world.” This mindset, while adding to his achievements, has also had a negative impact. “While it is a good way to respond to society, we have to remember that we are not living for the society, we need to do things we want to do.”

The other speakers resonated with Vineet and said how this pressure to overperform and be overachievers has made them feel guilty and hesitate in asking for accommodations. When Surashree was in college, she was expected to climb multiple flights of stairs because her classroom was on the 4th floor. “There is a particular expectation that you will adjust in any ecosystem,” said Surashree, “Especially when they see me dance and swim, they believe that it is okay and easier for me to go to the fourth floor. And because everyone told me ‘Oh you are so strong, you are such an inspiration’, I imposed it on myself to not talk about the things that I was uncomfortable with, and to accept what people expected out of me.”

Soumita said she cannot work 16-17 hours a day and she will not but this comes with a lot of guilt. “It took me a lot of courage, a lot of hospitalisation and a lot of mistakes to just say that this is what I can do, this is what I will do and we will see where it goes.”

Disability also comes with fluidity. There are days when you need more accommodation and there are days when things are easier, said the panelists. And this discomforts the society, said Nidhi Goyal, Founder and Executive Director of Rising Flame.
“The world has a sense of discomfort with anything fluid, anything that changes from day to day, said Nidhi, “Because it just doesn’t fit their worldview and it does not fit a narrative. And narratives are really important when it comes to businesses because we build a narrative around who’s the leader. What does a leader look like, how does the leader function? How leaders should have superpowers and work 36 hours in 24 hour days. And what does it do to people who may have different demands on your body and your mind?”

Aditi realised during her first job that she needs to create a system that works for her. Working in the advertising sector meant long hours and routinely being on ad-shoot sets which are dominated by non-disabled men. “I realised that this neurotypical way of working was not working for me,” said Aditi, “I needed to create a system that will work for me.”

She discovered she was autistic and had ADHD when she was 23. After her diagnoses, she started reading about it but did not relate to it because most of it was written about little boys and men. Lack of information on autistic women and autistic non-binary people, prompted her to start her media company, Much Much Media, which is geared towards telling stories of disabled people, told by disabled people. Within 3 years of starting Much Much Spectrum, a branded content division of the media company, they have been able to amass more than 25,000 followers on Instagram.

At Much Much Media, Aditi is trying to build a diverse team led by women who have the space to create their own ways of working without being bound by the 9-5 grind. “I work the best at night and the rest of the team have their own time and space to work around things,” she said.

Surashree also said that she is committed to creating a diverse team with a goal of 20% of her staff comprising persons with disabilities. But she faced a lot of backlash because of this, especially with investors. “When you go out and ask for investments and you say that you want a particular section of your employees to be persons with disabilities, they start seeing your organisation from a non-profit organisation perspective, rather than seeing it as a for profit organisation which wants to provide these opportunities,” said Surashree.

Her entrepreneurial journey began during her school time. Surashree, who was born with multiple hereditary disabilities including clubfoot and limb length discrepancies spent most of her childhood in hospitals as a “guinea pig for everything”. She had her first surgery when she was 15 days old and by the time she was 15, she had had 25 surgeries. This meant months of missing vacations and schools. During this time, a slam book was her best friend. Before the academic year would end, she would get all her classmates and teachers to fill the book and over the next few months, this book and these entries gave her a lot of mental peace and happiness. Her venture, ‘Yearbook Canvas’ had its genesis in the hospital beds and has now become the number 1 yearbook company in India.
Another key barrier for persons with disabilities to occupy leadership positions is stigma, according to Vineet whose company, Atypical Advantage, aims to provide dignified livelihood opportunities for disabled people.

“When we approached companies to hire disabled people from IIMs, we expected the same package as they would offer an able bodied person,” said Vineet, “[Companies think] that disabled people can be hired for entry-level positions because the stakes are lower. And that they cannot do tougher roles or senior roles.”

Vineet who started his company after losing his job during COVID-19 has in the last three years through his company got Rs 1 crore income for artists with disabilities.

They are worried about ‘what if something happens’. Also, most of them haven’t seen enough persons with disabilities in mid level or senior level positions.”

Vineet said that while tags like being an alumni of an IIM has helped him with securing funding easily, other entrepreneurs face bias. “Investors think that entrepreneurs who are disabled might not be more productive or be able to produce higher returns on investment.”

“Each of us at some stage have been questioned on our abilities,” said Nidhi, “People perceive you as not a complete entrepreneur, not a capable entrepreneur.”

Hustle as a disabled entrepreneur is more hustling, said Soumita and advised entrepreneurs with disabilities to take small steps, ensure that they have a lot of savings and the right ecosystem of partners and mentors. She also said that making your business model lean and ensuring a sustainable basic income is essential to be able to succeed as an entrepreneur.
What role does gender play in caregiving? How can we create networks of support for caregivers? What do these networks look like?

Caregiving NOT a solo job

Important to create networks of support: family, neighbours, friends, community, professionals.

Family is an important resource. A collaborative, family-centred care giving is more effective. Good to involve grandparents, extended family. Grandparents can often set the tone for the entire family.

Employers and organisations should extend support to parents of children with disabilities.

Need for systemic change, systems of support in society to help both parents and children with disabilities.

Caregiving is isolating and challenging. Caregivers need care too.

- Taboo and stigma around disability. Mothers of disabled children are often excluded from social celebrations, and end up isolated.
- Lack of awareness about neural bleeding disorders makes the journey of navigating caregiving harder.
- You must be responsible for this, you gave birth to him: Caregivers are often blamed.
- Women tend to take on more responsibility without looking after their own needs. More prone to stress, anxiety and depression.
- Lack of awareness about sign language makes deaf parents dependent on CODA (children of deaf adults) to play the role of interpreters.

“Put on your own oxygen mask first! What are you doing to look after yourself and your needs?”

Put on your own oxygen mask first! What are you doing to look after yourself and your needs?

If we accept what each parent brings to the table, look for the multiple ways kindness and care manifests, water these, we can build trees of connection.

"In most parent-child relationships, a line/boundary exists. The line between us and our parents doesn’t exist. Parents might need us to translate something that other parents might not normally share with their children."

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Panaji: In December 2019, Sabina D’Cunha’s mother told her to quit her job in Dubai and return to India. Sabina’s one-year-old son had developed bluish-black bruises on his body and multiple visits to the doctor had not led to a diagnosis.

Three months later, as investigations continued, Sabina’s son cut her tongue while eating a chocolate. She tried to use home remedies to stop the bleeding but it refused to stop, forcing her to rush him to a hospital. The stringent lockdown created many barriers for her to seek healthcare but eventually he was diagnosed with a rare congenital bleeding disorder—Glanzmann Thrombasthenia.

“It took me 3-4 days to memorise this name,” said Sabina who is the secretary to the Hemophilia Society Panjim chapter Women’s group. Because of the disorder, her son’s body does not have the ability to stop any bleeding and each wound could be potentially fatal. He has to be monitored 24x7.

While narrating her ordeal at a panel discussion on gender and care at the International Purple Fest Goa 2024, Sabina said, “Caregiving comes with acceptance. If you do not accept then it is always going to be a burden and you will always be stressed about it.”

On an average, women in India spend more than 3 hours each day on caregiving, 75 minutes more than men, negatively impacting their happiness, satisfaction and health.

Taking care of yourself and accepting any help that you get is integral to ensuring caregiving doesn’t become a burden, said panellists which included Jo Chopra McGowan, Executive Director at Latika Roy Foundation, Nandita DeSouza, Director of Sethu Centre for Child Development, Prachi Arora, an Indian Sign Language Interpreter & Child Of Deaf Adults (CODA) and Sabina. The panel was moderated by Barsha Banerjee, the Managing Director of Perkins India.

“Caregivers are care needers,” said Nandita while explaining long-term impacts of stress. Nandita, who is a developmental and behavioural paediatrician, has worked with more than 7,000 children and their families since the beginning of Sethu in 2005. “Under stress, our body secretes cortisol and adrenaline which makes us more alert, increases our heart rate and pumps more blood into our muscles. This is helpful for short term stress like a job interview or exam.

But as a parent, the stress is 24x7 and these super helpful hormones and neurotransmitters start hurting your body. Your blood pressure goes up, you are not able to sleep, you start feeling depressed and tired. So there is a very scientific reason why you should put on your oxygen mask first.”

“What has come out is that women are primary caregivers in all cases,” said Barsha, “When we have children come to our intervention centres, we rarely see fathers. It is always mothers or in some cases grandmothers, but it is always the women.”
Jo, who has also been a caregiver for her adopted daughter Moy Moy for 28 years, also stressed the need for asking for help and building a community. Moy Moy, born in 1989, was born on the side of a frosty road in remote Garhwal with no medical attention. Being three months premature, she had severe disabilities, including mild cerebral palsy. Till the age of four, she had remarkable progress, being able to walk, talk, feed and dress herself. At the age of five, she developed seizures and by 10, she could no longer speak and required help from two people to get around. By 16, she had quadriplegia, used a wheelchair exclusively and ate with a feeding tube and by 28, she was completely dependent on her parents, Jo and Ravi.

“Being a caregiver is something that you can embrace and make it a life changing event or you can take it on as a personal burden.”

While addressing the shifts in both parents while caring for their child with a disability.

“People are not aware and people don’t know sign language,” said Prachi, “Even close family members think they have kids to help with communication so why should we learn sign language.”

When she was 5, her parents took her to a government office for the first time as they needed to sort out some issue about their pension. “Even the official there was wondering what a 5-year-old would say,” said Prachi, “But I knew I just needed to interpret.”

As a CODA, our bond with our parents are very deep, she added, “Generally, there is a line between parents and children where parents do not share some things with children and vice versa but for CODA, that line does not exist.” Recently, Prachi had to act as the interpreter for her father when he had to visit a doctor for a personal problem. “At one point, I felt really shy and was wondering how do I tell this to the doctor,” said Prachi, “But at that time I had to remember that I am here as an interpreter and had to keep that shyness aside and work as an interpreter.”

“Others start realising at 20 or 25 that their parents are dependent on them but I had this realisation when I was 5,” said Prachi, “There have been times when it has been exhausting and my responsibilities have increased as they have become older. But I know that I only have to do it.”

But not all caregivers are parents. Prachi grew up with deaf parents and sign language is her mother tongue. More than caregiving, Prachi said, she was a mode of communication for her parents.

Barsha stresses on how we need to think of caregiving as a whole within the family. She said, “It is also important for us to see this in the context of societal norms that primary caregivers have to deal with and the stresses this then results in.”
To be able to not see caregiving as a burden, one has to seek help and support. One has to build a community like a bouquet of flowers and seek help when they need it, said Jo, “I have to say that I can’t do everything. I can’t afford to do everything physically, mentally, emotionally or financially. It’s not possible. So somebody else has to step in.”

“Being self-reliant is important but it is also necessary to let others do some things for you,” said Barsha, “It is fundamentally okay because we tend to try and take everything on our own.”

But for many, that help is not easy to come by. Women bear a disproportionate burden for caregiving and Nandita believes communication and getting families on the same page is key to ensure caregiving doesn’t become a burden. Nandita said often parents have a difference in opinion or understanding of the issue. Fathers, many times, believe everything is fine, the child is fine and that the mothers are overthinking and getting stressed but mothers feel that everything is not fine. This leads to women becoming lone parents, said Nandita, “Not being able to discuss it makes the burden heavier.”

But the isolation, many times, extends beyond the family to communities. This could be because of self isolation or stigma.

“Many of the mothers that we work with self-isolate,” said Jo, “They don’t go to weddings or festive occasions because they perceive that people around them see it as bad luck.”

Sabina had to face similar stigma in her family and community. “Everyone started blaming me,” she said, “They said it is because of black magic or because I must have eaten something wrong during pregnancy. A few people started distancing themselves because they thought I would ask for money.” Three years since the diagnosis, Sabina now has three jobs to be able to sustain as a single mother.

Family-centred care is going to make the biggest difference, said Jo, adding that community awareness is also important.

Nandita said that removing blame and moving towards appreciation is important to bridge the communication gap.

“Look for those little seeds or shoots of kindness or caring in whatever way they manifested,” said Nandita, “By watering them with appreciation, valuing it, I think you can move to trees of connection and support.”
How does disability affect gender identity and gender roles in day to day life? How do ideas of beauty and attraction shape gender performance?

You anyway won’t conform to beauty standards set for women. You won’t ever be at par with able bodied women. So why even try?

What is a beautiful body?

Disability is normally seen as the opposite of everything that is beautiful. It is seen as undesirable and ‘ugly’.

Common trope in literature and media to represent ugliness using disability: Richard the Third by Shakespeare, The Hunchback of Notre Dame.

Generally implied that disabled bodies won’t be seen as attractive, conform to society’s normative beauty standards.

Attraction seen differently in the disabled world and the able bodied world.

Physical accessibility acts as a barrier for me to have a relationship, because men don’t want to date someone who can’t accompany them everywhere. It’s not like I don’t want to go places, but most public spaces are inaccessible to me.

One friend said he would be more open to marrying a deaf or blind woman as opposed to a woman with crutches, since the former is more socially accepted on the standard of beauty.

Communities can be safe spaces

Queerness is a big part of my life. My chosen family has taken the time to listen to get to know me for me, and allowed me to break down my walls.

Disabled and queer communities are reimagining the ways they want to live and are redefining relationships, beauty, attraction, sex and family.

Ace community’s outlook on attraction which looks beyond gender and sex, and looks at connection, is liberating.

Queerness is also about visual performance, about being seen. Being blind, I can’t participate in that performance. I am not aware of how to dress, or what colours to wear to be ‘queer enough’.

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Are you a man? Are you a woman? Why do I have to be anything? Why can’t I be EVERYTHING?

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There is fetishisation of disabled bodies by cisgender-heterosexual society.

Nobody in my biological family ever asks me who I am dating, or who I am into, even though they ask my cousins. They don’t even consider that I might have those kinds of feelings.

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Performing Gender roles

A lot of male bonding is based on able-bodiedness. Deprived of that experience as a disabled man.

Male alienation: Don’t fit into certain categories of masculinity.

Women are not only scored on their ‘desirability factor’, but also their potential to be a perfect homemaker and perform ‘Bahu duties’. Able bodied people struggle to connect disabled women with that role.

Cisgender Heterosexual people struggle with gender roles the most, because of their rigid ideas about what is and isn’t acceptable. They are the ones thinking about this

Excluded from ‘men’s world’ and doing ‘men’s work’ as a disabled man. Excluded from decision making. Included with women but only out of pity.

I’m not in a constant panic about my masculinity in my queer circles because I don’t have to constantly perform my masculinity there, the way I have to in cisgender heterosexual circles.
Panaji: Ishan Chakraborty’s challenges with navigating gender began early in his life, during his school days. He was the only blind child in his school in Kolkata and he felt the acute gender segregation, especially during sports periods. While boys in his school were supposed to go out to play cricket, basketball and volleyball, girls were expected to stay inside the classrooms and play “women’s games”.

And because he never used to go out to play with the boys, he was constantly bullied, by students and teachers. “People used to say things like ‘you are not playing with men so you are not quite a man’ and call me ‘ladies’, ‘chakka’ (a derogatory term for transgender people) or other similar derogatory terms that are hurled at ‘effeminate’ men,” he said.

On the other hand, the girls in his class would include him only because they pitied him. And he faced such exclusion within his home too.

“I was never expected to do ‘men’s work’ like carrying heavy luggage or rushing to the market last minute or fixing some tech issues”, said Ishan, “And whenever a decision is to be taken in the factory, I never used to be consulted. Decisions used to be just dumped on me.”

Like Ishan, many disabled people have to deal with these kinds of societal perceptions on their gender. No matter how much they try to confirm, they are never considered “man enough” or “woman enough” and are reduced to their disability. These perceptions are not just limited to gender. Society constantly perceives disabled people as either asexual or hypersexual, even fetishising disability. These issues were discussed at a panel discussion on disability and masculinity, femininity and gender fluidity at the International Purple Fest Goa 2024.

Ishan, who is an assistant professor at Jadavpur University was one of the speakers along with Sweta Mantrii a writer, disability inclusion enable and a standup comedian and Shivangi Agrawal, a disabled queer activist and artist in the panel that was moderated by writer, editor and disability rights activist Abhishek Anicca.

Sweta has always loved dressing up and looking good but she was constantly dissuaded

“There were instances when I was dressing up, wearing lipstick or choosing matching accessories, close family members have said something like ‘You don’t need to dress up because people are not going to focus on you because of how you look but because of who you are’,” said Sweta.

Comments like these have dealt a huge blow on her self esteem, effects of which are still present today, Sweta added.

“The implication here is that anyway you don’t conform to the beauty stereotypes or standards of a cis-het woman and if you try, you will never be at par with non-disabled women,” said Sweta, “So don’t bother.”
Gender is a social construct and it should not be such a big part of our lives, said Shivangi, while detailing an altercation she had with the security personnel at the airport. Her wheelchair could not get into the stall so she asked the female security personnel to conduct the check outside the stall. But she said, “No no no. This is not allowed in India”. “She is inconvenienced by the embodiment of gender even though she is pushing it so much,” said Shivangi, “It is cis-people, especially non disabled cis-people that struggle the most with gender. They are constantly thinking about gender and trying to confirm gender and these roles. But they will never be able to fit in, no one will.”

“The idea of normal continues to haunt us,” said Abhishek adding how the idea of beauty and attractiveness and how it is presented in movies, advertisements and social media shapes a lot of perception.

The easiest way to represent “ugliness” in culture and media is to introduce some kind of physical impairment or disability, said Ishan while listing examples of the hunchback king in Shakespeare’s Richard III and Quasimodo from Victor Hugo’s The Hunchback of Notre Dame. “Disability is considered to be the opposite of anything beautiful,” he added, “It is undesirable.”

And these social standards that are propped up by popular media affect our lives, said Sweta, who a decade ago, for a documentary asked her male friends if they would marry a disabled woman. A friend of hers said that he would be okay marrying a blind or a deaf woman as opposed to someone who uses crutches, as she will at least be socially accepted based on the standards of beauty and because a person who uses crutches will not be able to accompany him everywhere.

Sweta said this was an eye opening moment for her. She also brought up something Abhishek had told her earlier. He had said, “Do you ever think that the boy you have a crush on is ever going to view you with the same desirability as he views an able bodied person?”.

“That shook me,” said Sweta, “I will never be able to be as sexy or desirable as an able bodied person. I will never be able to pose in a way a non disabled person poses for a photo and maybe that makes all the difference. I may also not be able to perform sexually as a non disabled person. But unfortunately these are the standards that affect our lives.”

When asked if there is a version of a universe where they can belong as a disabled person as you are, all replied the existing universe but urged the people to be accepting and inclusive.
“I do not want the world to change in any way,” said Ishan, “But I want to assert my difference. I have the right to be different. I have the right to live as a person with inherent dignity. I am a person with inherent dignity, and have the right to be perceived and received as such.”

“The universe I want to exist in is now because it has taken a lot of unlearning and accepting myself to be comfortable with not fitting into a narrative,” said Sweta, “I want to continue to be a rebel and resist the narrative that the society wants me to surrender to.”

“Disabled people and queer people are redefining, reimagining and adapting to a lot of ways that they want to live and trying to embody that into the world as well,” said Shivangi, “I really want the world to embrace these changes and try to reimagine what everything looks like, whether it is attraction, beauty, sex, gender, relationships or families.”
What is a 'good' parent? How does one deal with the constant doubt on one's parenting capabilities? What are the very real challenges as a disabled parent?

Challenges of being a disabled parent:
- Deaf parents cannot rely on sound cues of a child crying so as to tend to their needs, and need to create other systems, such as sleeping close to the child, relying on technologies like sound sensors.
- Parents with mental illnesses, especially those who have extended periods of not functioning, can struggle with day-to-day tasks of parenting, such as creating a structure at home, drop the kids on time.
- Mental illnesses make it difficult to prioritise things, have stable moods, manage impulses, handle stress, stay organised. This makes parenting even more challenging.
- Children of parents with disabilities often take on more responsibility at a young age, or one unable to be their full selves out of fear of distressing their parent. This is something no parent wants for their child.
- Lack of accessibility in public spaces can make it difficult for a parent to meet their child's needs. For example, hospital visits where there are no sign language interpreters, etc., dropping children off to school where infrastructure is inaccessible.

Dealing with judgement and blame:
- The harshest judgement often comes from family and those closest to you, and hurts the most.
- Disabled parents treated like children and not capable adults by family.
- "My parents told me not to have children, but I had children. They say I should not sign with my kids, but how else am I supposed to communicate with them?"

There is no perfect parent. It is important to acknowledge where we need to and have to grow. Parenting is a challenge for EVERYONE, and every parent is trying their best.

Finding support systems:
- Parents with physical disabilities lean on caregivers to support them with physical aspects of caregiving.
- Neighbours can help alert deaf parents if their child is crying and needs attending to.
- Therapy is helpful for parents with mental illnesses to develop tools and techniques to handle things better.
- Support groups of parents with disabilities and talking to other parents is helpful in navigating challenges of parenting.
- Your partner, friends, family and extended family can all step in as systems of support.
- Parents can also enlist the help of their own children, openly communicate their challenges with them.

"I tell my children, I won’t be like other mothers. I’m gonna try my best but I need your understanding."

"I didn’t teach my child to sign to make them an interpreter, but to communicate with my child, so as a family, we are bonded and can live a happy life together."

"My child and I have a very good bond and a loving relationship. She has always understood that her mom has come difficult.

"In my mind, there is a constant doubt. Am I a BAD parent? But also, compared to what?"
4. Disabled Parenting

Panaji: When Prasad Joshi wanted to get married, his parents told him to marry a hearing woman but he married a deaf woman. After he got married, his parents told him to not have any children because they might also be deaf. And when he had a child, they told him to not sign to him. They said, “Don’t sign in front of him. Then he will not speak or hear and will become deaf.” Prasad said, “That makes no sense to me.”

“One day I asked my parents, ‘why are you afraid of sign language?’ This is my language. This is the language I communicate to my child in. Why are you stopping them from signing now,” Prasad shared, “If I am not able to connect with my child and communicate with him, how will I understand their needs and provide for them?”

Prasad is the founder and general secretary of the Goa Association of the Deaf (GAD) and was a speaker in a panel on disabled parenting, along with communications professional Sandhya Menon and Jeeja Ghosh, consultant at Enable India. It was moderated by researcher and lawyer, Dr. Shikha Silliman Bhattacharjee. The panel Disabled Parenting took place on January 12, 2024 at Purple People organised by Rising Flame within the International Purple Fest 2024 in Goa.

Parents with disabilities have to constantly fight stigma within families and in societies. They are constantly perceived to be less capable than non disabled people and face constant pressure to prove otherwise. Parents are meant to provide care and nurture their children but because disabled people might need care sometimes, they are not seen as caregivers and are considered fit only to receive care. They also have to deal with constant accusations that they might be harming their children and face constant pressure to conform to higher and impossible standards. And often these judgements come from the most immediate family members.

For instance, Sandhya, who has bipolar disorder and borderline personality disorder, has been told by her parents to put her children into a boarding school.

Bipolar disorder causes changes in mood, energy and activity levels leading to periods of depressive lows and manic highs. Borderline personality disorder impacts a person’s ability to manage their emotions, negatively impacting interpersonal relationships. These illnesses make it difficult for Sandhya to instil a routine for her household.

While there are some days of chaos, most days are relatively calm. “I cannot provide calm space on a regular basis but there are a lot of good days. If there are 10 days of utter chaos, there are 20 days of calm in a month,” said Sandhya.
As a parent with a disability, Sandhya needs a lot of support, she said, “There are days when I just cannot wake up. Now my kids are old enough to get dressed and make a little breakfast and go to school. But when they were younger, I couldn’t. I couldn’t move.”

Both of her illnesses also give her a temper, she said, “While most parents might be kind and gentle when the child is upset. Even if it is a 15-20 minute tantrum, I tend to get distressed within 5-10 minutes.”

“I know when I am doing it that I should not do it. There is a part of my brain that tells me to stop and that I am hurting a child that is dependent on me,” she added.

And it is more difficult because she is a single parent, she said, “There is no second parent to balance it out.” And this has impacted her children. “My children have had to grow up quicker than most other children in terms of that.” Two months ago, her son told her that when most of the kids go back home there is a system, a routine. But when he comes back home, sometimes there is a routine and sometimes there isn’t and everything is a mess.

Sandhya faces a lot of judgement for her parenting, but for her the worst is when it comes from the family. Her parents told her to send her kids to a boarding school so that they would have a structure, a routine and she would be able to focus on her work. Her sister told her that she should not do this to her children and that she is not capable of looking after her children.

She is more gentle with outsiders, she said, because they don’t see them on a day-to-day basis. When people ask her if she should have had children and if she should be alone with them and not wonder if her children would have a terrible life as adults, she says, “I don’t know. How good of a parent are you?”

Jeeja, who was the first woman with cerebral palsy to adopt a child in India, also faced questions about her ability to take care of the child when she applied for adoption. “As an activist, I really wanted to be able to respond to them and stand out,” said Jeeja, “But I also realised that it is a difficult position to be in. Finally, with the support from an agency, I was able to sort out a lot of the problems and we were able to adopt our child.”

There are two aspects to parenting—the physical aspect of caregiving and the attitudinal aspect,

“Often I had to lean on other people for support for the physical aspect but when it came to bonding, my daughter has always understood that my mother has some difficulties.”
The panellists discussed handling these challenges around stigma with a firm grounding and a knowledge that they may not be what society holds up as the “normal” parent but knowing that they are parents who have something to give to their children, said Dr Shikha, “The bonds [between the parents and their children] are strong, and the bonds include an understanding of what the parents strengths are, as well as what some of the challenges are.”

Like Jeeja takes help with physical caregiving, both Prasad and Sandhya have adopted strategies to work around the challenges they face.

*When Prasad’s son was young, he and his wife used to sleep very close to him. “If she starts crying, either my wife or I would wake up and look after him and we would not disregard him for hours.”*

There are also applications nowadays that detect sound and have light-based alert systems that can be of use. But communication is the most important part, he said, “Now my child understands that he needs to tap me on the shoulder and not shout my name.”

Sandhya said talking to her children about mental illness and talking to other parents and creating a community has helped. Constant reflection and therapy has also played an important role in her journey of managing her illnesses, she said.

Building communities of support, they all shared, have been a boon to their journeys as a disabled parent.
What measures can be taken to improve accessibility and mobility for disabled people? How are gender marginalised persons disproportionately affected by their absence?

**Inclusiveness in planning and design**

- Universal design is design that is accessed, understood and used by the maximum user base despite age, gender, disability, etc.
- Physical accessibility has also become interlinked with digital accessibility. For example, you now need to navigate an app to be able to get access mobility (a cab).
- AI has a lot of potential to improve accessibility: screen descriptions of images for blind people, translating oral language to sign and vice versa for deaf people, reducing speech difficulties for people with cerebral palsy, etc.
- Need a cross disability inclusive approach when designing. Including a ramp is not enough. Disability is diverse and so accessibility needs are diverse.

Gender marginalised persons and people with disabilities need to be consulted and involved in planning, policy making and on ground. Their lived experience is invaluable.

**Intersectionality in understanding access: Disability, Gender, Caste all contribute**

- Women with disabilities are at higher risk of not having the same access to education, which can be an equaliser and open doors to opportunities.
- Women generally have less access to digital spaces. If there is one smart phone in a family, it is generally with the male member.
- Disabled women are more vulnerable to sexual violence. Many have reported men trying to harass them under the pretext of guiding, and taking them to secluded spots.
- As a deaf blind woman, I need support with communication in public spaces. I need someone to sign or spell on my palm, but I cannot always trust strangers.
- Public transport is cheaper or free, but inaccessible and unsafe. A lot of families are hesitant to spend that much more on a girl's education.

**Making transport and mobility more accessible**

- This is a shared responsibility of both government and private transport providers. Accessibility needs to be made a core mandate, especially with public procurements. Need updated standards of accessibility, fixed after consulting people across disabilities. Accessibility Impact Assessments need to be done regularly.
- “We are currently in the process of procuring thousands of electric buses. This is a huge opportunity to make the infrastructure inclusive from the get go, instead of retrofitting accessibility at a higher cost.”
- Transport operators need to be trained and held accountable, and given road maps to make products and services more accessible.
- Transport services are a largely male dominated space. Women with disabilities need to be involved at multiple levels: planning, policy, backend, actual on ground employment, etc.

This is not a one time activity or investment, but needs continuous efforts to do monitoring, evaluation and reporting.

Ensure NO ONE gets left behind.
5. Gender, Accessibility and Mobility including assistive technology and devices

Commuting alone comes with a myriad of challenges for Shrutilata Singh who is deaf-blind. “While my deaf friends and blind friends are able to commute alone relatively easily, I need support with communication,” said Shrutilata, “If I have to understand what a person is saying, they have to sign or spell on my palm. With so many issues of violence against women, the issue of safety is always a concern. I cannot just give my palm to anyone.”

And Shrutilata’s fear is a reality for many women with disabilities.

“Women have frequently told us that men have tried to harass them under the guise of providing assistance,” said Apoorv Kulkarni, the Head of Research at OMIFoundation that does extensive research on transportation, gender and disability, “They have told us about how men try to take them to secluded spots or touch them inappropriately.”

Even with proper assistance and support, women with disabilities are ignored by bus drivers and conductors because they are not acknowledged as customers. And after boarding the transport, there is a huge dependency on the drivers.

The issue of cost also makes public transport inaccessible for women with disabilities. Less than 6% of the public buses in the country are accessible, said Apoorv, while more accessible modes of transport like metros are 2.5 times more expensive, which would mean spending more to be able to commute.

Shrutilata and Apoorv were speaking at a panel discussion on ‘Gender, accessibility and mobility’ at Purple People organised by Rising Flame at International Purple Fest Goa 2024 on January 13, 2024. They were joined by Anubha Singhal, co-founder and director of Enable Me Access and the conversation was moderated by Antara Telang, Partner-Digital at Gnothi Seauton. The keynote address at the panel was given by Shri Rajesh Aggarwal, Secretary, Department of Empowerment of Persons with Disabilities, Ministry of Social Justice and Empowerment.

In his keynote address, Shri Rajesh Aggarwal addressed the trajectory of making election booths accessible across the country to ensure that persons with disabilities were able to cast their votes independently. He also spoke about the lack of accessible physical and digital public infrastructure and stigma and how it reduces mobility and independence of persons with disabilities, especially women.

“Mobility of women or girls with disabilities is much less than the mobility of boys or men with disabilities,” said Aggarwal, adding that a lower proportion of women with disabilities are beneficiaries under government schemes.

“If there are 100 people with disabilities, the proportions would be around 55 men and 45 women,” said Aggarwal, “But, this proportion gets skewed for disability cards with more men than women having the cards. When it comes to assistive devices, two thirds of them are going to men while only a third are going to women.”

“Public places don’t have basic accessibility systems in place. And when they do, they’re often not enough or they’re not done right,” said Antara,
“There might be a ramp but it might be too steep or there might be tactile tiles in one part of the building but not the other.” And these barriers deepen for disabled women and non-binary people because they don’t have the same access to education or face higher risk of violence.

The lack of safety leads to girls being forced to stay at home, and not being allowed to complete their education, said Shrutilata, “I know many girls with deaf-blindness whose parents are not comfortable sending them even with other people.” Parents are overprotective because they worry about safety and routine news of violence does not help.

But accessibility is not just about commuting or about safety. All spaces need to be created in a way that is equally accessible to all, said Anubha, who is an architect who lives with limb-girdle muscular dystrophy. Anubha, recently had a fall which gave her a knee injury and made her temporarily dependent on a wheelchair for the first time. It was an eye opening experience for her as she realised the specific challenges faced by people who use wheelchairs.

“Understanding the needs of different people with disabilities is not very easy until or unless we have experienced different conditions,” said Anubha, stating the need for adopting universal design principles.

“Universal design is a design which can be accessed, understood and used to the greatest extent possible by all users across age, size, ability, gender or disability,” said Anubha.

Antara, who had to start using a prosthetic leg after an accident she had when she was 18, resonated with Anubha’s statement. “Until 18 I was living a “normal” life and the accident and having to wear a prosthetic leg completely changed my perspective on life,” she said, “Until that point I had never really thought about it except for some passing thoughts that there should be a ramp in a building. It is only when you live that experience that you start realising just how deep the problem really goes and how we have normalised it.”

Anubha said lift is a great example of universal design and that it is not difficult to implement. It is more about awareness, building capacity and knowledge and actively involving disabled people in the design process.

Lack of accessibility also leads to economic losses, added Apoorv, explaining how if a young girl has to spend more on a rickshaw to college, her parents might consider telling her to drop out as the extra amount can be used to fulfil other financial needs of the family. A disabled woman working in an organisation might lose out on career advancement opportunities because she is not able to travel to meet clients. And a young mother who wants to provide the best education to her child, also has to consider which school she might be able to drop her child to.
“It is incumbent upon us to put in place an infrastructure that is empowering, enabling, so that people in general, but women with disabilities in particular, are able to create a present, and invest in the future for themselves, the families and the countries,” said Apoorv.

Accessibility begins with information, said Shrutilata, “I knew I had vision and hearing problems but I was not aware about accessibility and how I can get support. I knew nothing about it until 10 years back when I joined an NGO.”

First step is awareness, said Shrutilata as information currently only reaches disability rights activists. “Young people need to be made aware of their condition and their rights,” she said, “I did not know that there are ways to make education and employment accessible by supporting people and technologies.”

At her organisation, Shrutilata is working to provide information to disabled people in a simplified form. “It takes some effort to maintain it but it is worth it,” she said, “Because in the end, we have to ensure no one is left behind.”
How does climate change affect people with disabilities, especially gender marginalised people? How can we build better capacity for disaster response and INCLUDE disabled people?

People with disabilities are more vulnerable

- 80% of people with disabilities live in low and middle income countries, which often bear the brunt of climate change.
- Psychosocial disabilities affect the body's ability to thermoregulate, which increases the impact of heat waves on their bodies.
- Survival on a daily basis can be a struggle for people with disabilities, and becomes even harder in the event of disasters.
- People with disabilities are often dependent on caregivers for support, whose absence in a moment of disaster can mean life or death. Loss of their caregiver increases their vulnerability and also impacts mental health.
- There are many barriers in accessing information on disasters and the climate crisis for persons across disabilities.

Exclusion of disabled people from climate conversations, planning and policy

- In the mainstream, we are talking about climate change as though it universally impacts everyone uniformly. But that hides various injustices and inequalities.
- Disability determines one's access to rehabilitation, further care and visibility in death records.
- Even in places where floods repeat, we don’t learn from past mistakes. There is a lack of response even after disaster happens.
- Disaster preparation currently is largely ableist, neurotypical, cis-hetero normative and foregrounding middle class locations.

People with disabilities have been largely invisible in conversations about climate change, even when they include indigenous rights and low income countries.

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Access to healthcare post disaster relief is affected not just by disability, but also by gender and caste. What should a Dalit disabled woman seeking medical care do if the doctor refuses to touch her?

People with disabilities often have a lot of guilt and shame when asking for help, which also has mental health implications.

Access to healthcare post disaster relief is affected not just by disability, but also by gender and caste. What should a Dalit disabled woman seeking medical care do if the doctor refuses to touch her?

People need to be made part of the conversation. Let’s hear it from THEM, what their needs are, ask them what is practical for them. Only after you have taken the voices of people with disabilities into consideration can you talk about universal design.
6. Disability, Gender and Climate Change

Panaji: Eight in ten persons with disabilities live in low and middle income countries and face increased vulnerabilities to impacts of climate crisis. But they are largely left out in policies around climate change mitigation and disaster management and even if they are, the focus is largely on how extreme weather events cause disability and not about what is happening to disabled people.

Because of increased vulnerabilities and limited mobility, there is an urgent need to devise and implement disability inclusive climate policies, speakers at the panel discussion ‘Disability, gender, and climate change’ organised at Purple People by Rising Flame on January 13 at International Purple Fest Goa 2024. The panellists included Raj Mariwala, the director of Mariwala Health Initiative, Pranav Sethi, a disaster risk reduction specialist and Pavan Kumar Muntha, founder of Swaadhikar and the discussion was moderated by Srinidhi Raghavan, Co-Lead, Programmes at Rising Flame.

“We need to change the discourse of what climate change means and the effects on oppressed communities,” said Raj, “There is some conversation on how low income countries are experiencing climate change and on indigenous rights and climate change. But persons with disabilities are completely invisible in these conversations.”

Giving the example of migration, Raj illustrated how even in nuanced conversations, persons with disabilities remain absent. Questions around accessibility of migration and who is able to migrate and if disabled people are migrating, do they get the social support are never asked.

The same neoliberal systems that are impacting climate change are also impacting disability, added Raj, urging the need for solidarity between climate movements and disability justice movements.

And before one starts looking at the impact of climate change on humans, one needs to look at the source of the problem and interconnectedness of life on earth, said Pavan,

“At the end of the day, we survive because our life is interconnected with the life around us. All the living organisms, including other animals, birds, microbes, plants and forests and their interactions with each other is what makes life on earth possible.” Understanding these connections are important to our understanding of the climate crisis and its impacts.

“We are also always looking at the impacts as a future occurrence and not as an absolute current existence of our lives,” said Srinidhi, “We really need to think about the current everyday impacts."
Across the world, the climate crisis is leading to increased frequencies and intensity of extreme weather events like floods, earthquakes and cyclones and disabled people are routinely ignored and left behind during these disasters, said Pranav. In 2013, Pranav was at the Pindar valley during the floods in Uttarakhand and he described how he found an old blind lady in a house that was split into two due to a landslide.

“She was living all alone and was still there despite the floods and landslides,” said Pranav, “There was no one to help her out. There was no relief that would have been provided to her. She couldn’t even ask for any help.”

And these disasters also put stress on basic resources. Pranav illustrated this with an example from Haiti and how the shortage of clean water post the 2010 earthquake led to people murdering others for a bottle of water.

“That is what disasters do,” said Pranav, “And if you are disabled, you are at the receiving end, you will not be able to survive.”

And even in places where disasters like floods repeat, there is no learning from past experiences, said Srinidhi, “This time also, during Chennai Floods, there were so many messages about disabled people not being able to evacuate on time.”

“The risk is out there and it enhances because of vulnerabilities that come with disability,” said Pranav, “And if you bring gender into it, the risk increases exponentially.”

Women and gender-diverse persons with disabilities are more vulnerable to sexual abuse and exploitation during disasters, said Raj,

“In the aftermath of Cyclone Amphan, many disabled women reported that they were unable to use the washrooms and bathing areas, not just due to lack of accessible washrooms, but also because of fear of harassment and abuse from men.”

Transpeople also face similar problems and such harassment and abuse also leads to mental health implications like anxiety, stigma, shame, which further leads to increased risk for mental health conditions, added Raj.

Existing biases and structural barriers also worsen the situation. The process of getting a Unique Disability Identity Card is not the same for all kinds of disabilities or for people from all genders, and having this card can determine access to rehabilitation and further healthcare, said Raj. And biases also impact access. During the Indian Ocean Tsunami in 2004, Aravani community, a trans community in Tamil Nadu were denied access to shelter. “What if you are a dalit woman with a disability,” said Raj, “What if the medical professional refuses to touch you?”

Moreover, research has shown that most persons with disabilities face guilt.
and shame for asking for help during these disasters, said Raj, which leads to further mental health concerns.

Disaster relief frameworks are ableist, neurotypical and cis-heteronormative, said Raj. Inclusion has to begin at grassroots level, said Pranav

“All these policies are ableist in their framing. They are created in 6x4 rooms by two or three people who are working tirelessly on a deadline. People with disabilities, especially women, are excluded and we see the repercussions of that when the next disaster happens.”

Beside inclusion in policy making, persons with disabilities also need to be included in discourse around the climate crisis and access to information is integral for that said Pavan. “Climate crisis has become an elitist discourse today,” said Pavan, “It has to be brought down to the grassroots level and everyone of us has to be able to understand it. Because we are experiencing it and we are going to be the victims of it and make our future generations victims of the mistakes that we do today.”

Urging everyone to take the driver seat in the fight against climate crisis, Pavan highlighted how human greed is the cause of it and we need to have a holistic understanding of the impact of climate crisis, not just on humans but also on other living beings and the ecosystem.
Panaji: It was 1994 and one of the most popular songs in Bollywood’s history was released. Wearing a white skirt and top, Raveena Tandon danced to the catchy tune while Akshay Kumar lip-synced to the equally popular words, “Tu Cheez Badi Hai Mast Mast”.

Almost two decades after Tu Cheez Badi Hai Mast Mast, Kareena Kapoor danced on a song named Lollipop for Dabbang 2. Biting an imaginary piece of chicken, she mouths, “Mai to tandoori murgi hu yaar, gatka le saiyyan alcohol se” [I am tandoori chicken, swallow me with alcohol].

These songs liking women to goods and meat opened up a conversation around objectification of women and consent at the International Purple Fest Goa 2024. The interactive masterclass conducted and organised by Rising Flame at Purple People on January 13, 2024 raised pertinent questions around consent, specifically on the complexities around consent for women with disabilities.

To illustrate the nature of consent around disability, Nidhi Goyal, Founder and Executive Director of Rising Flame described a scene from the 2014 film Margarita with a Straw. In the film, Laila, a teenage girl with cerebral palsy, played by Kalki Koechlin, has a crush on a boy and is planning to see him perform the next day.

She is in the bath and her mother is assisting her when she says she wants to wash her hair. Her mother says no, she just washed it the day before. But she insists and her mother relents. “The mother expresses her opinion but does what she wants to be done. And that respecting when someone is asking something is the crux of consent.”

This kind of everyday consent is integral to the dignity and autonomy of disabled people. Recognising and respecting these needs and wants is built on the understanding that persons with disabilities are capable of making informed decisions and have complete rights over their bodies and lives. But this consent and autonomy for women with disabilities exist in the context of larger societal perceptions on women’s bodies, agency and autonomy.

“The reason we are using Bollywood is because that’s a classic example of so many issues around consent,” said Nidhi Goyal.

“Why is consent important, why is consent getting complicated, why is consent getting violated?” asked Nidhi, “We cannot discuss that unless we address, ‘Ek Akeli Ladki Khuli Hui Tijori Hoti Hai’” (The popular dialogue from 2007 film Jab We Met states that a lone girl is akin to an open safe.)

It basically means that once the safe is open, you can access anything, she added, “We are basically giving the idea that women are cheez, women are maal, women are tandoori chicken and if they are alone, they are an open safe. That means you can access if she is alone. Now we don’t know if that means alone at home, alone on the street, alone with the family or alone in life. So the messages are powerful.”
It also pushes a message, especially with respect to harassment, that if you are alone, you are asking for it and this puts the onus on women and femme-presenting individuals, said Srinidhi Raghavan, Co-Lead, Programmes at Rising Flame.

This kind of messaging and putting the responsibility on women also impacts the kind of space they occupy in public spaces. When participants were asked to mimic what a man and a woman looked like on the street, they instinctively knew how to occupy more space as a man. The person mimicking the man had a spread out stance with arms and legs wide. But the person mimicking the woman had her hands crossed with the eyes on her feet. “If I am in a public space, I would have my purse covering me or my arms crossed,” said the participant, “I am just minding my own business and want to get home as soon as possible.”

And disability changes these kinds of gender vulnerabilities and it differs for different kinds of disabilities. “When we are talking about gender impacting posture, it is also important to note that disability impacts the same,” said Nidhi.

As much as gender plays a huge role in shaping how we experience the world, disability plays another role, added Srinidhi. And how a person occupies space also leads to perceptions about consent. “It goes back to the open safe concept,” said Nidhi, “She is loud, so she is less respectful. She sits awkwardly, with her legs spread, which means she is inviting people.” And it is these perceptions that make consent complicated. For example, in this video, Raj who likes his colleague at a salon, stalks her digitally and persistently tries to woo her.

After 2 months, she agrees to go on a date but when they go to a mall for the date, she says let’s be friends. He says she said no a couple of times but he did not relent because he thinks she was shy. She ended up quitting her job to join another salon and filed a complaint against him. He does not think he stalked her or harassed her. He adds that this is what happens in films.

“This is why we started with Bollywood,” said Nidhi, “What is the famous dialogue in Bollywood? Ladki ke na mai haan hoti hai, which means if a woman says no, she needs more attention from you, so that she can say yes.”

It is not just men who believe that, added Nidhi, “Many women think the same and that they should keep saying no until they get enough attention. It is not about one gender or another. It is about how our thoughts as a society are getting shaped.”

Consent is contextual but it is foremost a relationship, said Srinidhi, “It is the relationship between two people built on them saying yes and no and the subsequent reactions.” Each one of these declarations of consent and its reactions becomes the foundation of the relationship.
When you’re living with a disability, you want to be with someone who chooses to look at you from beyond the narrative that society has chosen for you. You want to be with someone who lets you be and doesn’t stereotype everything that you do. You want to be with someone who wants to love you with your disability, and not inspite of it.

-From excerpt read by Sweta Mantrii.

The world is seeing persons with disabilities out and about, in education and in work places, asking for their rights. Yet an area of their lives still remains relatively shrouded in silence. Where persons with disabilities are routinely dismissed and rejected, made to believe the worst. Disability, friendships, relationships and love is as complex as it can get. Primarily because of stigma, people’s attitudes, but also the belief that somehow in intimate and personal spaces persons with disabilities are simply not full human beings, not capable enough.

Many young disabled people I meet these days have the same questions that I did. They have also been conditioned to believe that they are undateable, just like I used to think. That’s just society trying to tell us what they want us to be. I refuse to let society set out the definition of disability.

-From excerpt read by Aishwarya Othena.

If it is not the stigma then it is the ignorance. People don’t know about disability in this non-disabled world and have no idea of how persons with disabilities navigate and thrive in their personal lives. Thus they come in with information that harms and impacts sense of self in the most difficult ways.

A boy I liked told me I’d ‘be better off moving to places like the UK or France’, where people could be more open minded about my ‘condition’. At that age, it was hard enough to deal with the new label of being ‘handicapped’ (no, I don’t need you to give me your hand every 30 seconds, thank you very much), but being thought of as ‘undateable’ was even scarier.

-From excerpt read by Antara Telang.

Adding gender to the mix increases the complexities and levels of push back. Where persons with disabilities are seen as undateable, asexual and so on. Women with disabilities are dismissed on further grounds of not being “women enough”. In a society where a woman is considered stereotypically to be the primary caregiver, women with disabilities are judged for also needing care and therefore ineligible for relationships and marriage.

Are you serious? Look at yourself, Kavita. You’re on a wheelchair. Do you think that I want a daughter-in-law that cannot do things by herself and that I have to help her, when she should be taking care of me? When Nayan told me that he’s dating someone on a wheelchair, I told him to do whatever he wants, but just don’t escalate this to marriage. I do not want a daughter-in-law on a wheelchair.

-From excerpt read by Virali Modi.

A woman is also held to a normative standard of beauty and is often made to feel bad for being “too dark”, “too fat”, “too tall” etc. There is a social perception and standard of beauty and perfection against which women are examined and their femininity is certified. For women with disabilities these standards further complicate love and attractions in a non-disabled world.
I also learnt about the 'body beautiful' concept. Traditionally women are only considered to look beautiful and that is it. Most men desire their women to be attractive and beautiful. As far as a disabled woman is concerned, she always gets unnoticed because her body is different.

-From excerpt read by Malini Chib.

Negative conversations, attitudes and beliefs on sexuality and desirability of persons with disabilities leads to a lot of distress in their lives and often accompanying this distress is the isolation and loneliness.

The Grammar of My Body
That’s a match
In my fantasies
I draw you
with a pencil
I draw myself
with an eraser

-From excerpt read by Abhishek Anicca.

Many disabled folks don’t delve into the areas of love, romance, sexuality etc. openly because of the taboo nature of these themes. To lift the silence, Rising Flame curated a reading session featuring six powerful writers which included famous Indian disability rights activist and author on who ‘Margarita with a Straw’ was based Malini Chib; writer, motivational speaker and India’s first wheelchair model, Virali Modi; writer of recently launched Penguin India book, The Grammar of my Body, Abhishek Anicca; writer Antara Telang; Research Scholar O. Aishwarya and comedian and disability inclusion enabler Sweta Mantri. The session was moderated by Preetam Sunkavalli, Manager, Business Transformation at Mahindra group.

The session brought together themes of dating, perceptions of disability held around us, its impact on sexuality of persons with disabilities and finally their own sense of self being impacted by these. Each of the writers shared a piece that explored how disability, sexuality come together to impact their everyday relationships and in turn the ways in which these have shaped us. Through the readings, we created a space for disabled people to see themselves, their relationships and their intimacies in different light.

You can access the excerpts read through the following links:
Abhishek Anicca: https://www.penguin.co.in/what-its-really-like-to-date-with-a-disability/
Aishwarya O: https://docs.google.com/document/d/1ZMW1LZ11mWg7qaPRPRABBSTWHoqCw22Hs73aJbJMM0w/edit
Antara Telang: https://blog.sexualityanddisability.org/2016/09/tender-ing-one-legged-girl-mumbai/