

Holding Space

Understanding Invisible Disabilities and Intersectionality - Part 2



Rising Flame is an award winning nonprofit organisation based in India, working for recognition, protection and promotion of human rights of people with disabilities, particularly women and youth with disabilities. Rising Flame's vision is to build an inclusive world in which diverse bodies, minds and voices thrive with dignity; live free of discrimination, abuse and violence; and enjoy equal opportunities and access. Since its establishment in 2017 as an organisation led by women and persons with disabilities, it aims to enable persons with disabilities standing at multiple intersections to have a voice, have a space, be heard and lead from the front. The organisation has a twofold strategy - to build capacities of persons with disabilities and to influence the ecosystem. Its major programmes are on leadership, mental health, sexual and reproductive health, gender based violence, research and policy influence. Rising Flame is known for its groundbreaking research Neglected and Forgotten - the first report across the world capturing the impact of the COVID-19 crisis on lives of women with disabilities. In 2023, Rising Flame also led the work across 20+ countries on Disability, Equity, Justice in India's G20 presidency. Rising Flame is committed to advancing rights while upholding disability justice and feminist principles.

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INTRODUCTION

With a recognition of mental health impact that persons with disabilities live through, Rising Flame presents this self-learning manual for mental health professionals and practitioners to make therapy spaces and mental health support more accessible and inclusive. This manual is the second in the series 'Holding Space' and will explore the diversities that persons with disabilities live with, the diversities of identities, contexts, disabilities and so on.

In our first manual titled 'Holding Space: Deconstructing disability experiences and navigating ableism in therapeutic conversations', we spoke about the ableism experienced by persons with disabilities in their everyday life, in schools, work places, homes and relationships. We attempted to make visible the effects of these experiences on their mental health through sharing lived experiences and learning from them.

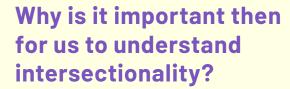
The experiences of disability are not homogeneous, whether the disability is visible or invisible, and depending on the intersections of other marginalisations experienced and the different contexts of life – family, friends, education spaces and workplaces – people experience their disability differently, they are perceived differently, they are 'allowed' or able to access services differently. In this manual we attempt to explore these complexities of disability experiences: disability and its various intersections and the particular experiences of those with invisible disabilities.

Often when one thinks of disabilities, invisible disabilities such as chronic pain, mental health conditions, neurodevelopmental and neurological disabilities are not necessarily taken into account in society's design of its structures, systems, and services.



Invisible disabilities by virtue of not being apparently visible, while sometimes allowing to pass as 'nondisabled' also carry with them the burden of always trying to pass as 'nondisabled' thus undermining and denying the challenges faced in an environment that is still not designed for all the diversities of being human. People experiencing invisible disabilities often experience the burden of 'coming out' as disabled every time they need to ask for access or worse, have to prove their invisible disability in order to 'deserve' access. The assumption and performance of 'normal' is something that people with invisible disabilities grapple with every day.

Experiencing other marginalisations based on gender, sexuality, caste, location, and others further compounds the challenges of disabilities and could increase the barriers to 'coming out', making it harder for people to access accommodations or access arrangements and making it more challenging to ask for them.



As Zainab (one of the people we interviewed during the consultation process of this manual) says
"I live with a locomotor disability, I have my set of problems. And then another person is also living with a locomotor disability doesn't mean that we have the exact same number of problems, it can be different, and we cannot be like 'Ye toh kar rahi hai tum kyon nahi kar rahe ho? (she is doing it why can't you do it?)"

"When you meet one person with Autism, you have met one person with Autism"

- Dr. Stephen Shore, American autistic professor of special education at Adelphi University.



The diversity within disability experiences is as numerous as persons with disabilities themselves. Intersections of marginalisations create circumstances that are very particular and it is important to pay attention to these particularities. While this manual could not in any way do justice to the vast experiences of persons with disabilities in all their diversity and all the intersections of marginalisations, we try to bring focus on intersectionality in our understanding of disabilities.

Access to services, the quality of services available and the support needed to access services all depend on additional identity marginalisations experienced by people, on whether they are believed in their experiences

or not. Do they live in an urban context, a big city or a small town or village, are they marginalised by caste, are they queer or trans, do they experience an invisible disability, or a rare condition - all of these aspects influence the access and quality of services. As mental health professionals providing services to persons with disabilities it is our responsibility to learn and inform ourselves of the diverse experiences of people with disabilities at the intersections of other marginalisations. It is a constant learning, and we learn as we do. We learn from the experiences of people whose stories we witness in our consultations; we learn from the various writings and stories of persons with disabilities that already exist. We learn and we unlearn.

This manual is an attempt to bring some of these experiences together for us to learn to deconstruct ableism and other systems of power that marginalise and oppress people and bring an intersectional understanding of disability in our work as mental health workers.



HOW TO USE THIS MANUAL

- This manual is created as a self-learning tool for mental health practitioners, educators, social workers and anyone working with person with disabilities. The exercises invite learners to read quotes, excerpts of articles, watch videos and consider questions offered for reflection.
- The exercises in the manual can also be used in assignments or in teaching as those from the first manual have been in the past. The manual can also be used to design workshops and trainings for practitioners and the self- learning exercises can be modified to group exercises.
- We hope this manual provides a structure to begin conversations on disabilities and intersectionality, and invisibility in your contexts of work whether individually or in teams and groups.



CONCEPTUALISING AND PRODUCING THE MANUAL

In our endeavour to bring a diversity of voices and their wisdom to this manual, we started the process by interviewing persons with disabilities at the intersections of various marginalisations and disabilities. These conversations have informed the structure and content of the manual. The quotes of the interviewees are used in the manual to help us reflect on the complexities of invisible disabilities and considerations of intersectionality.

The manual has been conceptualised, informed, authored, edited, and reviewed by experts who live with invisible and visible disabilities and have worked or lived closely with persons with disabilities.

Dr Prathama Raghavan, an experienced mental health professional, is the author. Nidhi Goyal and Srinidhi Raghavan both women with visible and invisible disabilities from Rising Flame have conceptualised, reviewed, and edited the manual. The interviewees have informed closely the structure and substance of the manual; the manual is scaffolded with their voices. To ensure holistic coverage of the discourse, we turned to our external team of reviewers Beena Mohan, Candice D'souza, Dr Neha Goyal and Dr Sharad Philip. Besides their expertise, they brought their lived experiences in their review. Two of our reviewers are persons with disabilities themselves and two are kin of persons with disabilities.

BRIEF OF OUR TEAM

Dr Prathama Raghavan (PhD):Author

Dr Prathama Raghavan has over 15 years of experience working on disability and mental health in India, Nepal and other parts of South Asia. Her work and life are informed by narrative practices, principles of disability justice, neurodiversity, transformative justice and poetry. She also worked in mental health, and wellbeing alongside communities in rural areas, those living in conflict, post-disaster contexts and with refugee communities in Nepal, Bangladesh, Myanmar and Afghanistan with humanitarian organisations.

Nidhi Ashok Goyal: Internal reviewer

Nidhi Ashok Goyal is the Founder and Executive Director of Rising Flame that works for leadership and rights of women, youth, and persons with disabilities in India. She has been working on disability rights and gender justice for the past 13 years at the national, regional, and global levelsthrough research, writing, policy influence, and art. Through her national and global work and advisory and board positions including at the UN, Dutch ministry etc, she has left an impact in 5 continents and over 30 countries.



Srinidhi Raghavan: Internal reviewer

Srinidhi Raghavan is the co-lead programmes, at Rising Flame. A disabled feminist, researcher, educator and writer, she has been working at the intersections of sexuality, gender, disability and digitality for the past 12 years. She has been a disability columnist and has been published extensively in national and international websites on gender, sexuality, disability and technology.

Beena Mohan: External reviewer

Beena Mohan is a certified special educator (RCI) and a counsellor. She has been working in the field of special education with children, adolescents and young adults for the past 20 years. Beena currently serves as the board member of Action For Autism. She is also an external member representative on the POSH Committee at Spastics Society Of Tamil Nadu.

Candice D'souza: External reviewer

Candice D'souza is a practising therapist living with cerebral palsy who works with children, adolescents, young adults, persons with disabilities and those with chronic / terminal illnesses. She is currently pursuing her PhD in Counsellor Education and Supervision at University of North Carolina, Charlotte. She is extremely passionate about the creation of inclusive mental health spaces and infrastructure particularly for individuals with disabilities.

psychiatry. He is an acclaimed clinical and teaching faculty at the Department of Psychiatry, Clinical Neuroscience, and Addiction Medicine. He holds diplomas in family medicine, medical law and ethics, and human rights law. He identifies as a person with a visual disability.

Dr Neha Goyal:External reviewer

Dr. Neha Goyal is a Mumbai-based practising dermatologist and cosmetologist since the past 14 years. A gold medallist doctor, and the sister of two disabled siblings, Neha is committed to offering affordable and quality health care to underprivileged persons and works to realise this goal through her practice at charitable hospitals and institutions; contributing expertise at free medical camps; and through volunteering to provide guidance on health and gender with charitable trusts.



Dr Sharad Philip is a distinguished psychiatrist with 13+ years of expertise in rehabilitation, complex case management, and diverse facets of psychiatry, including child and adolescent psychiatry and addiction







PART 1:

INVISIBLE DISABILITIES

in·vis·i·ble dis·a·bil·i·ty

/in'vizəb(ə)l/ /disə'bilədē/ noun

In simple terms, an invisible disability is a physical, mental or neurological condition that is not visible from the outside, yet can limit or challenge a person's movements, senses, or activities. Unfortunately, the very fact that these symptoms are invisible can lead to misunderstandings, false perceptions, and judgements.

<u>Definition from</u> Invisible Disabilities Association

Invisible disabilities refer to disabilities that are not immediately apparent or visible to others as explained in the definition above. These disabilities may include chronic illnesses, mental health conditions, cognitive conditions, neurological and neuro-developmental conditions, and other conditions that do not have visible physical markers or assistive aids.

The challenges associated with invisible disabilities stem from the fact

that they are not readily observable, leading to misconceptions, and a lack of recognition and support. When invisible disabilities are fluid conditions, changing from one day to another or from one week to another - perception of people and support needs are further complicated as they may be different from each day or week to the next. Disabilities like multiple sclerosis, autism spectrum, or conditions such as bipolar disorder, epilepsy, schizophrenia, chronic pain to name a few, are fluid and dynamic disabilities/ conditions with some days, weeks, months having less access needs than other days, weeks, months.

To begin our reflections as we delve deeper into invisible disabilities, here are some quotes from our consultation interviews for this manual:

the world, it was anxietyinducing. There's a sense of
fear because the expectation
is that this person will come
and say something from
their mouth. That is the way
communication is expected
to happen. So, this is the
divide between the Deaf and
hearing worlds or entities. The
language divide automatically
presupposes a judgment,
looking down upon, or a basic
manifestation of ableism.

- Hardeep Singh (he/him), 24, Deaf, artist and multimedia designer, from New Delhi, quote from interview with Rising Flame **CC** My diagnosis of bipolar disorder and borderline personality disorder - I didn't realise that they were disabilities. When I was diagnosed, in my universe, or in my world, or the thing that I was reaching out to, and interacting with, this was not seen. I mean, I didn't, I was not exposed to the language of this being a disability. Although, it should have been and it should have struck me also, because when I am in my manic phases, I'm not sleeping for 1, 2, 3, 4 nights, right? And I'm staying awake till I'm delirious four days later, or, you know, borderline psychotic four days later, where I have to be hospitalised. And that's putting me out of any productive work or any productive relationships or any anything for a good two weeks after that, right.

. . .

A lot of us with invisible disabilities because we live in a world that is ableist... I am not very fond of that word but it is a good word to describe that the world is built to a standard, to a norm

that makes up a large number of people, it's not malicious, it's not deliberate... it leaves people like me out because if you don't have the language for something, you are never going to know what it is.

It is only in the last 10 years I have started to hear of mental illness as a disability. If that was a more common point of view, then you won't call yourself lazy, you won't call yourself unmotivated, selfish whatever the horrible words you end up calling yourself or others end up calling you right. So, you're just stuck in this corner believing you are lazy, selfish, terrible. That there was no language for it, I didn't know it was a disability... I am still getting to grips with seeing this as an invisible disability and what it does and how it gets in the way of things.

• • •

With this kind of diagnosis, we just say no, we're just like everyone else. And this is just a part of us. And it's not a disability. That's an extremely

strong denial. I still experience it, right? Fighting myself to get things done. I feel like the idea that this is a disability, helps in fighting myself just a little less, you know, just a little. And it is, as in life becomes easier when you loosen those strings, right? >>

- Sandhya Menon, communications professional living with mental illnesses, quote from interview with Rising Flame

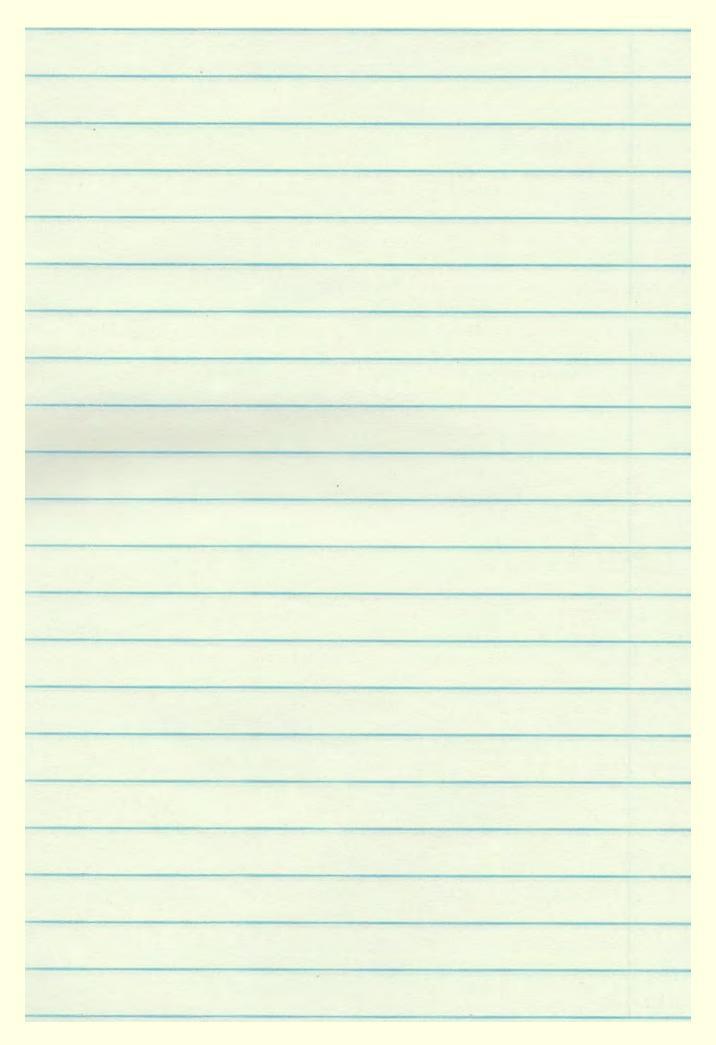
Questions for reflection:

1. Reading the quotes above, what are some of your first thoughts on the difficulties of navigating the world with invisible and fluid disabilities?

2. What makes it invisible and who is it invisible for?

3. What do you think is the impact of invisible disabilities on the daily living of people who live with them?





Sandhya describes her condition as fluid – varying support needs from one moment to another. The fluidity of the condition could lead people around to either not believe the distress experienced or not have faith in the skills of this person. It also leads to living with a certain uncertainty:

'When might my condition flare up?'
'When might I need to disclose my condition?'
'Will I be believed if I have been functioning seemingly 'normally'?'





Disclosure of the disability or requesting the access arrangements required is also affected by the responses of the environment to these demands.

invisible may also have to convince other people that they really are disabled....

Thus, what they must do is meet a burden of proof. They thus face a double bind: either they forgo the assistance or accommodation they need – and thus suffer the consequences of attempting

to do things they may not be able to do safely by themselves – or they endure the discomfort of subjecting themselves to strangers' interrogations.

- N. Ann Davis in her article titled 'Invisible Disability' in the journal Ethics published in 2005 retrieved from Maggie Arin Korn's dissertation titled 'Being a man with an invisible disability: College Men's experiences'.

4. From the quotes above and from experiences people may have shared with you in therapeutic conversations, what challenges do you think a person may face in accessing support when their disability is invisible?

The particularities of invisible disabilities include having to 'come out' in every new interaction, figuring out whether to disclose and when to disclose and how to know who is safe to disclose to, navigating the complex and fluid needs and advocating for individualised access needs that are dynamic. Invisible disabilities means that people are not automatically perceived as having a disability. This perception has an undeniable effect on the person experiencing the disability themselves in acknowledging the challenges they face in their lives and in typical environments. Am I disabled? Is this a disability? Normative ideas that disability is always visible or only certain 'physical' conditions being considered as disability, further alienate people from coming to understand their conditions as disabilities.

As Sandhya says in her quote, acknowledging an invisible condition as a disability allows people to perform normativity and productivity a little less perhaps. What role could we play in this framing as mental health workers? How could we support people to acknowledge the conditions they experience as disabilities? How we could we bring attention to the discourses of ableism in our conversations with people experiencing invisible disabilities?

Being protected from discrimination by the invisibility and at the same time not receiving accommodations and access arrangements can have effects on a person's sense of self, relationships with friends, family, colleagues, employers, and overall wellbeing. Bringing attention to this in therapeutic conversations may allow the person to acknowledge this for themselves. Therapeutic conversations may also support them in advocating for themselves.

'How do I reconcile the 'passing as non-disabled' and asking for access arrangements and accommodations when I need them? How do I disclose and 'prove' my disability in order to 'justify' needing accommodations? How do I respond to the denial and ignorance about the particular disability I experience once I disclose it? How do I explain that I may need some kinds of supports on some days and not need them at all at other times?'

These are some questions amongst many others that persons with invisible disabilities grapple with.

Given that the public image of disability is one that is visible, static, predictable, and needing certain kinds of supports – people living with invisible disabilities and fluid, dynamic conditions may struggle with acknowledging their need for support as valid or real. The unpredictability of not knowing what the days are going to be like with a fluid or dynamic condition – requires not only navigating the uncertainty of it but also navigating the perceptions of people about the disability and the support being requested.





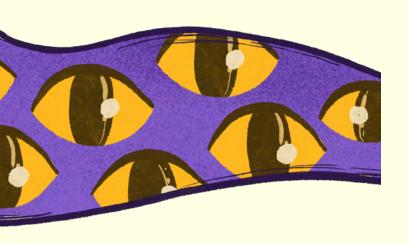
WITNESSING AND AFFIRMING ONE'S EXPERIENCES

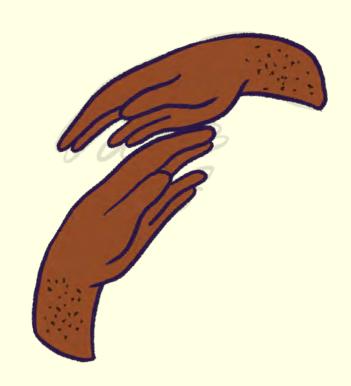
In this video by Much Much Media,

'Navigating life with multiple disabilities and chronic pain' – Anindita Kundu, Disability Self-Advocate, Psychotherapist, speaks about the different conditions they experience and the challenges of navigating the world with these multiple and dynamic conditions.

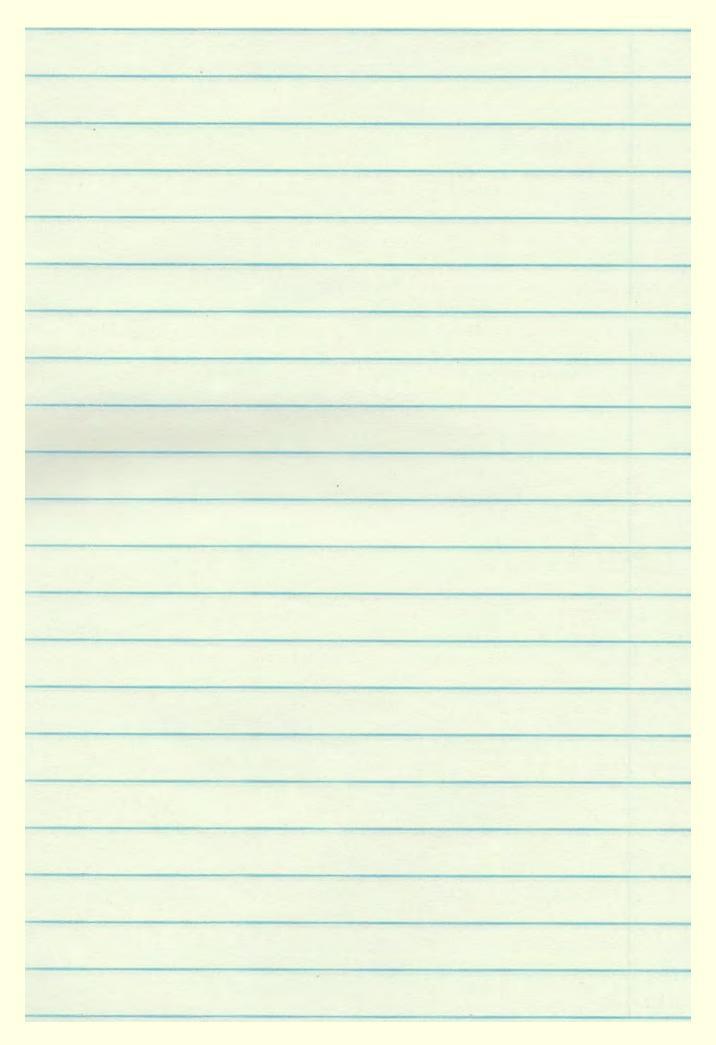
<u>Watch the video</u> before returning to these questions:

- 1. What are some things that stand out to you about their experience?
- 2. They speak about the difficulty of acknowledging their experience of pain and the narrative that the pain is 'normal' or it needs to be discarded in some way. What does this get you thinking about the importance of acknowledging chronic illnesses as a disability?





- 3. What effects do they speak about on their mental health of the chronic pain conditions they experience?
- 4. They speak later about the effect of 'affirmative care' acknowledgment that what they are going through is true. Why might this affirmative care, this acknowledgment of lived experience, of believing people's experiences be important? What does it make possible for the person's sense of self?



Being acknowledged and being seen in one's experiences, being witnessed is one of the most important intentions of mental health work. People being witnessed in the complexity and particularity of their story is important. Identification of conditions, having a name for something you experience – offers the possibility of this witnessing though it shouldn't be necessary.

In finding community with people who experience similar conditions, people find resonance and support that they are not alone. This experience of resonance helps in alleviating the alienation and loneliness they might be experiencing from their conditions. When people come to us and tell us their experiences and tell us that it is about caste or their gender or sexuality or disabilities or chronic pain conditions or all of these, we become witnesses to that, we carry that understanding to other conversations with other people who consult with us. We believe them and we learn to be better witnesses.

We will explore chronic illness conditions further through <u>this</u> <u>interview of Jennifer Brea with Srinidhi</u> <u>Raghavan for Point of View about her film 'Unrest'.</u>

Jennifer Brea is an independent filmmaker based in Los Angeles. She has a Bachelor of Arts degree from Princeton University and while studying for her PhD at Harvard she fell ill leaving her bedridden after an acute viral infection. Her Sundance awardwinning, Emmy-nominated feature documentary Unrest was shortlisted for an Oscar. By 2012, she progressively

lost the ability to read, think, or walk. Finally, she was diagnosed with myalgic encephalomyelitis (ME), (commonly called "chronic fatigue syndrome," a condition that is the same or similar to what many people face with "long COVID").

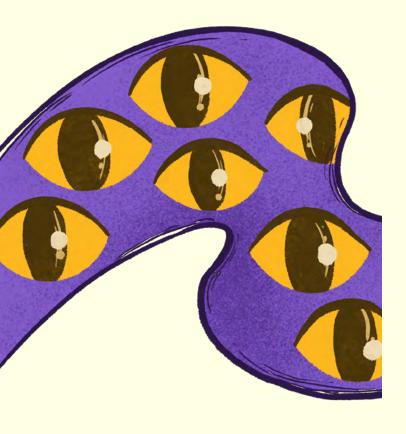
Jennifer Brea in this interview with Srinidhi Raghavan also talks about this witnessing of her experience and making it into a documentary. She speaks about the experience of sharing her fears and her difficulties of living life as a human and all the roles one plays in that life.



- 5. What does this interview get you thinking about the difficulties of accessing a diagnosis or an identification of conditions of chronic pain and chronic illnesses? What effects do these challenges have on people's sense of themselves?
- 6. What effects might these challenges of accessing a diagnosis have on people's mental health?
- 7. What difference would it make if you took these understandings from Jennifer's interview into your practice with people living with chronic illnesses and pain conditions? What might you do differently?

Srinidhi speaks in the interview about the power of finding resonance and the support she received when she wrote her article about her own diagnosis and the struggles with that. They talk about needing more stories about these experiences.

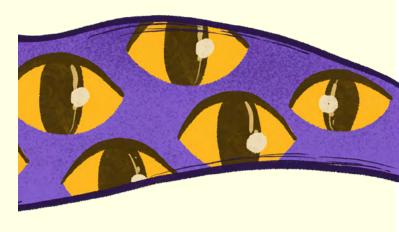
In this quote below we see Jennifer Brea's experience of being vulnerable and finding her community.



- 8. What difference would it make for people living with invisible conditions to have more stories about others experiencing similar conditions?
- 9. What are some ways you could make this more possible for people who consult with you, who may be experiencing invisible disabilities?

C It was really scary to share those moments, these fears about starting a family and what does it mean to be a human being if I can't walk or I can't do the things that I used to be able to do, if I can't be the wife I want to be to my husband. Sharing these things was really hard the first few times. But you start to hear stories of people in the audience, people who have the same conversations and the same moments and the same fears. That really taught me the power of art and of storytelling. There is nothing we live or live through that someone else has not also experienced. In acknowledging that and in not feeling ashamed about it by sharing it and build community. >>

- Jennifer Brea, independent filmmaker





INVISIBILITY AND MASCULINITY

In this video in an interview with Much Much Media titled 'The reality of living with epilepsy', Ninad Salvi, talks about the experience of living with epilepsy as a child and as a working adult. He speaks about people's perceptions of his invisible condition.

ce If I get a seizure on the street, people will think, such a grown man, a working adult is falling on the street, they will think twice about marriage with me or even friendship with me.

He goes on to speak about the

sympathy of people and how he doesn't appreciate it all the time. Disabilities invite sympathy and often pity and lead to a dismissal of people's skills and abilities. Ninad talks about how he navigates his everyday life, his skills, his passions and his future plans.

Here is a quote from another male identifying person, Anthony who lives with Obsessive Compulsive Disorder (OCD) from <u>Maggie Arin Korn's</u> <u>dissertation titled 'Being a man with an invisible disability: College Men's experiences'.</u>

Anthony had difficulty opening up to others, particularly his male peer group. He attributed this difficulty directly to his masculinity. He said:

Just like being a guy, most guys are usually stereotyped to not share their feelings and be emotional and stuff, so it's definitely harder for me to share the fact that I think I do have OCD to all my friends and all the guys in the fraternity 'cause it might make me look like weak or like...I don't know... but just like based on society standards...I was kind of hesitant to share that information with anybody besides my close family.

10. Listening to Ninad's interview and reading the quote from Anthony – what does it get you thinking about invisible disabilities and masculinity? What effects does gender socialising

of people assigned male at birth have on how they acknowledge their disability experience and whether or not they seek support?

11. What consequences of being 'found out' as having a disability do Ninad and Anthony refer to – in their professional lives and their personal lives? How might these perceived consequences influence them asking for support and access arrangements?

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Referring to Anthony's experience above Maggie Arin Korn in her dissertation says

CAnthony acknowledged that being a part of a society that pressures men to be tough, strong, and in control of their emotions has made it difficult to be open with others about his disability. Like independence and toughness, the idea of success permeated participants' narratives and was connected to their ideas about masculinity.

Bringing this understanding of the influence of masculinity on the acknowledgement of disability is important to our therapeutic conversations with people who identify as men, and those who have been socialised as male from birth. Deconstructing the ableism inherent in the hyper masculine, patriarchal discourse becomes part of the therapeutic process.

We go back here to the ideas of 'acknowledging as a disability' that Sandhya mentions, 'affirmative care' that Anindita speaks about and the 'difficulties of accessing a diagnosis' that Jennifer Brea speaks about.

As therapists we hold space for people to explore and honour their diverse ways of being. As therapists

to people experiencing invisible disabilities our responsibility falls firmly in being witnesses to their experiences, to acknowledging and articulating the ableism and pressures of normativity inherent in the world around us, in nurturing a sense of self that is supportive of these ways of being without denying the distress experienced and the support needed. In addition, we take into account that access is the responsibility of mental health workers and not only the persons with disabilities themselves. We place the problem firmly in the discourses of normativity and productivity and not in the bodies and minds of the people who consult with us.

In Rising Flame's interview with Hardeep, he emphasised the need for mental health professionals who use Indian Sign Language (ISL). Speaking about making services accessible, he says mental health professionals should:

communication preferences, learn ISL themselves, and involve themselves more in the Deaf community.

He speaks about the responsibility of access falling not only on the person needing mental health therapy but on those providing these services. What are some steps we could take as mental health professionals to make our services more accessible to D/deaf and hard of hearing people?

WHAT DO WE MEAN BY ACCESSIBILITY?

Accessible means that something is designed or modified in a way that allows people with disabilities to use it or access it without encountering accessibility barriers. Accessibility is all about ensuring that everyone, regardless of their abilities or disabilities, can access information, products, services, and environments in a way that is inclusive and equal.

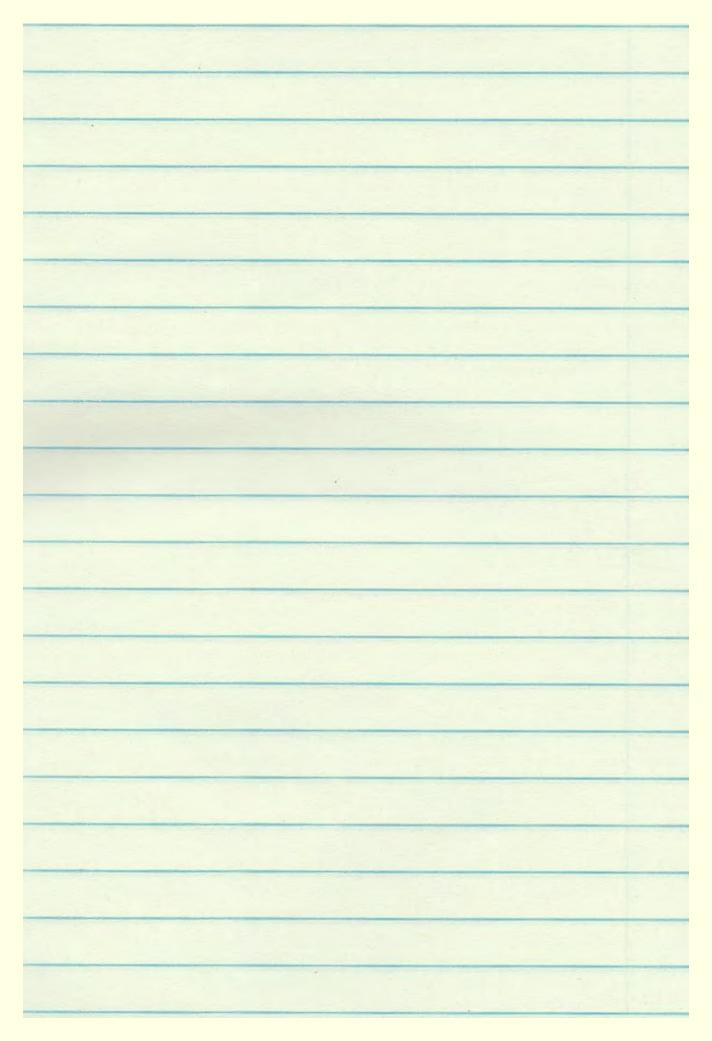
Definition from Hand Talk

Thinking further about access and how it is both affected by and affects the disregard for persons with disabilities and their agency in society and the world in general, brings me to the perception of non-speaking autistic people and the harm that it has done to them being perceived as 'lacking any capacity for communication'. We know now from many non-speaking autistic people who communicate using text to speech devices or text boards how damaging the professional world's perception was about them and their 'capacities' and their 'functionality'. Please see resources by non-speaking autistics in the additional resources section at the end of the manual. Here is one video of autistic self-advocate Aditi Sowmyanarayanan on the Much Much Media show titled 'Non-speaking does NOT mean 'non-thinking'.

The videos, articles and quotes shared centre the experiences of persons

with disabilities in their own words and in their particular contexts of life. Diversifying the stories of persons with disabilities supports us as mental health professionals to draw from varied experiences in supporting those who consult with us and in understanding more and more diverse disability experiences. The intention of this manual is to do just that, to bring stories and experiences to expand our understandings through lived experiences. Where are you in your thoughts about invisible disabilities? Take a moment to write down what are some things you want to take away from these videos and readings.

- 1. Why might these understandings be particularly important to mental health professionals? What might this acknowledgement by mental health professionals make possible for people consulting with us?
- 2. What are things we need to understand better or know better in order to make this more possible? What are some steps you could take towards that?
- 3. How can therapists make everything from their office spaces to their procedures for intake and therapy more accessible to people with invisible disabilities?



PART 2:

DISABILITY & INTERSECTIONALITY

Recognising the intersections between disability and other identities helps us understand the unique challenges and experiences faced by individuals who navigate multiple forms of discrimination and marginalisation. It highlights the complex and interconnected nature of social inequality and allows for a more comprehensive understanding of an individual's lived experiences. Understanding disability requires an intersectional lens. Access and inclusion need an intersectional lens. If we do not look for intersectional stories, we end up in an echo chamber with needs and challenges that are not inclusive of ALL persons with disabilities.

Here are some quotes from our consultation interviews for this manual we would like you to consider before we delve into deeper reflections on intersectionality.

CC As much as we are having a conversation about neurodivergence, it's still not wide enough. Most people still don't look at autism like it could exist like this. But they know about the other identities a little more and caste is like one of the oldest ones that they're familiar with, but they've never acknowledged it. So, I don't know how much of their behaviour towards me is coming from caste because it is a very direct connection that we know because as a Dalit person you are someone who is not accepted. Because



you're considered deviant as a person. And deviancy means of course sexual deviancy. So, then queerness comes into that. Queerness also means like mental deviancy and that is like the autism.

. . .

Wherever I go, I am seen more like an anomaly – not expected to be here. And there is the thing where you're constantly seen as incapable. But then also, you're seen as someone who can handle any kind of adversity. But then, of course, that level of like survival is not seen as capability.

. . .

A lot of time goes in figuring out who you are because you can't rely on anyone's opinion around you.

- BRC, Author (Ze/Zir), autistic, as told during the consultation interview with Rising Flame disability, I navigated through it, that was a lesser part, but most of the problem which I felt was because of my religion, there were Islamophobic comments.

Also sometimes, you know, in discussions, there was things like these things women can't do, or these things women should not do. So these kinds of ideas brought me closer towards feminist ideas.

 Zainab (she/her), lawyer, lives with locomotor disability, as told during the consultation interview for this manual







WHAT IS INTERSECTIONALITY?

'intersectionality

/IˌntəˌsɛkʃəˈnalIti/ noun

noun: intersectionality; plural noun: intersectionalities

The interconnected nature of social categorizations such as race, class, and gender as they apply to a given individual or group, regarded as creating overlapping and interdependent systems of discrimination or disadvantage. Through an awareness of intersectionality, we can better acknowledge and ground the differences among us.

understand the history and struggles that lead to the articulation of the intersectionality framework <u>watch</u> <u>Professor Kimberlé Crenshaw's TED</u> <u>Talk.</u>

You can also read more about the framework of intersectionality and multiple discriminations in this article: <u>Intersectionality and Multiple</u> <u>Discrimination</u>.

<u>Definitions from Oxford Languages</u>

First coined by Professor Kimberlé Crenshaw back in 1989, intersectionality was added to the Oxford Dictionary in 2015 with its importance increasingly being recognised in the world of women's rights.

This video explains intersectionality

in the context of multiple identities to understand better. As we go further, we will explore intersectionality in the particular context of disability. To





WHAT IS DISABILITY JUSTICE?

Disability Justice is a framework that understands disability from the intersectionality perspective and rejects the claims or demands of independence and moves towards interdependence - beyond the disability rights movement and calls for collective access and liberation, for cross-disability and cross- movement solidarity. To read about disability justice in more detail, read the ten principles of Disability Justice by Sins Invalid.

'A disability justice framework understands that:

- All bodies are unique and essential.
- All bodies have strengths and needs that must be met.
- We are powerful, not despite the complexities of our bodies, but because of them.
- All bodies are confined by ability, race, gender, sexuality, class, nation state, religion, and more, and we cannot separate them.'

Reference: What is Disability Justice?
Adapted from Patty Berne's Disability
Justice - A working draft referenced
from the Sins Invalid website.

CC We are pushing for an understanding of how ableism affects all of our movements for justice. We are drawing connections between ableism and other systems of oppression and violent institutions. We are pushing for a more nuanced and fierce interrogation of the medical industrial complex and understandings of health, wellness and healing that aren't rooted in ableist notions of bodies and what is considered "normal." >>

- Mia Mingus, Changing the framework: Disability Justice.





Questions for reflection:

1) What are some things that are standing out to you from these definitions of Intersectionality and Disability Justice?

2) Disability Justice is moving from demands of independence to interdependence in the definition quoted above. What does the idea of interdependence make more possible?

3) What are some considerations about intersectionality and Disability that it is getting you to think about?

The first manual, 'Holding Space:

Deconstructing disability experiences
and navigating ableism in therapeutic
conversations' has a quote from Cal
Montogomery's essay: Critic of dawn
where he explores ideas of dependence
and independence.

He says "None of us of course is independent... We grow up in social contexts, supported and denied, enabled and disabled by those around us. Some rely on support, which is so common as to go unnoticed, while others use support that is atypical and therefore apparent."

You can delve deeper into the deconstruction of ableism and the

ideas of dependence and independence through the exercises in the first manual.

WHY DISABILITY & INTERSECTIONALITY?

The intersectionality and Disability Justice frameworks are important not because we need to interrogate people on the various marginalisations they experience, but that we assume and acknowledge that multiple marginalisations exist and we all live within the confines of that and that they are many times not readily visible. We need to understand that experiences are different based on these marginalisations. For example, we need to check our assumption that any person with disability consulting with us is and will be heterosexual or cis-gender or from a privileged caste. There may be situations where one or the other marginalisation is more evident; there may be many situations where that is hard to discern. But irrespective of this, people at the intersections of various marginalisations experience lack of access and agency, discrimination, disrespect and disregard in complex ways.

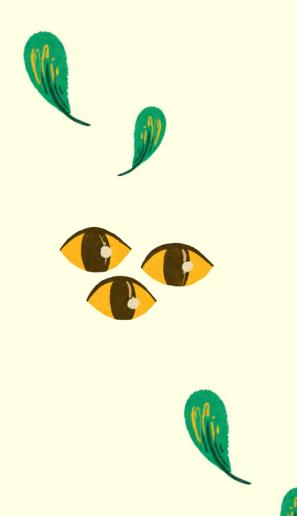
With disability experiences it is essential to have the intersectionality framework and listen to and acknowledge people's diverse experiences, and interrogate our own positions of privilege and the world views that overlook these diverse experiences.

We want to start our reflection on intersectionality with this quote from

Mia Mingus's keynote speech at the 2018 Disability and Intersectionality summit titled 'Disability Justice is simply another term for love'. This was the opening keynote speech at the 2018 Disability Intersectionality Summit, in Cambridge, Massachusetts on Oct 13, 2018.

The official video recording of this keynote.

<u>Transcript from Leaving Evidence – Mia</u> <u>Mingus's blog</u>





Who understands disability, ableism, abled supremacy; the medical industrial complex, histories and notions of cure, ugliness and the myth of beauty; race, white supremacy, orientalism, adoption, transracial adoption, transnational adoption, the commodification and ownership of children, immigration, forced migration; Korea, diaspora, US imperialism, war, borders; the Caribbean, colonization, the US South, anti-black racism, slavery and the US slave trade system; misogyny, patriarchy, sexism, gender, domestic and sexual violence, child sexual abuse; feminism, queerness, queer people of colour; rural lands, islands, rural communities. And how all of these intersect with each other.

I wonder what the things needed to hold your stories are? I wonder how many pieces of your story weren't told because there wasn't anyone who could understand and hold them? I wonder how many parts of all of our stories that we still have never told anyone because of this? >>

- Mia Mingus, writer, educator and trainer for transformative justice and disability justice



In the context of India, South Asia and South Asian communities worldwide, we must consider the intersectionality of caste and indigenous communities, in addition to the ones mentioned above. We cannot fully understand disability in all its diversity if we do not acknowledge and understand marginalisations based on caste and the colonisation, displacement and oppression of indigenous communities in addition to sexuality, gender, class and rural communities.

Jyothsna Phanija's [in conversation with Pragya Roy for Feminism in India in an article titled 'In Conversation With Jyothsna Phanija: Where Caste, Disability And Gender Meet'] reflections add to what Mia shares and highlights why an intersectional lens is so important in our work with persons with disabilities.

successful disabled people, who have been able to make a mark in society, many of them are from the higher castes.
When studies are conducted on caste, disability is not included. When disability related research is conducted, caste factor is not taken into consideration. From ages, learning or the space and resources to learn rests with higher castes.

. . .

The real challenge I still face is explaining myself every day. Non-disabled people are hurtfully curious. At this age, explaining how I work on computers with a screen reader, how I manage my phone with voice over, what are the adaptations I made to study and do household tasks, looking after the house and children, are not so easy all the time at all the places. Learning about the lives of the disabled people, is not rocket science.

Rachelle Bharathi Chandran in
Navigating healthcare as a Dalit, nonbinary person with debilitating social
anxiety says:

those of us who are marginalised by sex, gender, religion, abilities without discussing caste. Caste plays a role in what help we get in terms of healthcare. It decides if we can get adequate care, blood transfusions, organ donations. It's that feeling of loneliness when we don't know of places where we can speak about our lives, and hope that our journey is understood.

Questions for reflection:

- 1. From reading the above quotes, what is your understanding of why intersectionality is important in the understanding of disability? What are some things it is getting you thinking about?
- 2. What do you think could be the complexities of navigating multiple marginalisations in everyday life in the context of
- a. School or University
- b. peer relationships & friendships
- c. workplace
- d. access to health and mental health services

- 3. What are some particular ways it may influence mental health of persons with disabilities at the intersection of various marginalisations?
- 4. What may get invisibilised or overlooked about their particular experience when they seek mental health support?
- 5. What are some ways you can think of to resist that invisibilisation? What are some steps you could take in conversations with people with disabilities to allow for this resistance to invisibilisation?

LINKING
DISABILITY,
DIVERSE
GENDERS
AND
SEXUALITY

In this video by Point of View, Mumbai, Candice D'Souza, a psychology teacher and therapist, who also lives with neurodivergence and cerebral palsy talks to Yashna Vishwanathan about disability and sexuality and taking a disability and queer supportive lens in mental health conversations with persons with disabilities.

She says:

itself is so hard because, you know the general perception of people with disabilities is that because they have so much else to contend with, sexuality will take a backseat or gender identity will be the default

because they are being looked after largely. Working with the assumption that they are still being provided with care one might assume that their care providers and doctors and other people have just treated them as most society and most authority figures do in a very gendered way. And therefore they may not have had time to really question or figure where on the gender continuum they lie. When

they do mention sexuality, queerness or identifying as trans, it can become difficult because firstly, to put ourselves in their shoes, because the dual marginalisation that comes with being both disabled and queer is a lot of systemic and structurally induced stress."

...

Say if they were to talk about contraception, about sexuality, about feeling gender dysphoria, the natural assumption perhaps would be that you know that's a later concern, let's talk about, you know the bias would naturally be towards thinking that a disabled client is coming in to talk about their disability, which is not necessarily an issue because for most people as least, of course when it is an acquired disability it is a very different context, because it will cause adjustment problems, it will cause distress. But for someone who has lived with a disability their whole life, like someone who knows they have had cerebral palsy or ADHD, or being born blind or with low vision, that's a part

of who they are, that's the only normal they have known, that's not going to be of course, it's a source of stress because the system is not designed for us but that's not always the only reason, like you wouldn't assume with a queer client that they are coming in to deal with their queerness, you don't want to assume with a disabled client that they are coming in to deal with that they are coming in to deal with their disability.

Candice speaks about the assumptions we may make about persons with disabilities – about their gender and sexuality but also about the fact that when they come to therapy, they want to contend with their experience of disability in particular which might not always be the case. Nevertheless, it is important to bring a lens of deconstructing ableism to all our conversations. We must make visible the discourses in the room in order to counter them and rescue the alternate ways of being that are inevitably present in people's lives.

She goes on to say that for persons with disabilities:

with not wanting to even think in that direction, in the direction of sexuality and gender identity initially because there's so much shame and guilt and

conditioning associated with saying, oh, but you know, you're special, you're different, or being infantilized also because even disabled adults, if not in the work place then at home, and if not at home then in the workplace are treated in a very infantilised ways. So when they start to talk about sexuality, it can be riddled with a lot of shame, hesitation and guilt. And if the therapist comes in with those ideas, you know and if they have even one experience where the therapist misgenders them or says, are you sure this is how you feel because also with a lot of physical disability, say I have a speech disability or say I speak a certain way that makes me sound like I don't have my thoughts collected, say I speak with a stutter? The assumption may be that I don't know what I want right, which is the assumption underlying most interactions with disabled people.>>

- 6. Read Candice's quote and note down three things that are important to keep in mind when talking about sexuality and gender identities with persons with disabilities?
- 7. What does this get you thinking about how you can challenge assumptions or the dominant ideas about persons with disabilities and their sexualities and gender identities in the work that you do?



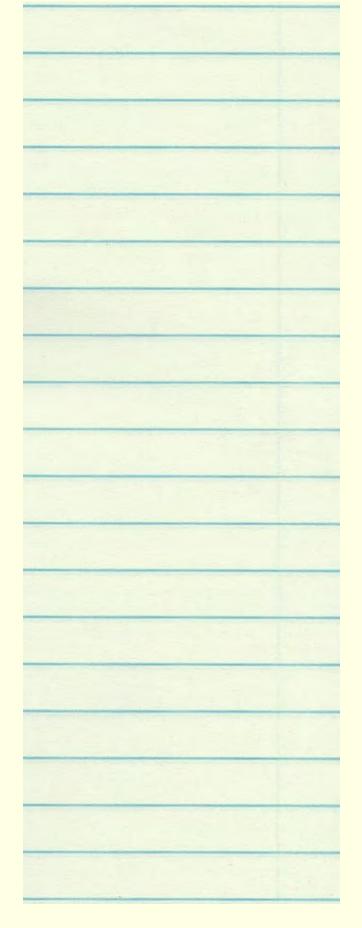


Candice speaks about the carefulness to bring to conversations when speaking of gender and sexuality with persons with disabilities in particular. She mentions the careful, tentative yet firm acknowledgement of their own understandings that is needed in therapeutic conversations. As she says many persons with disabilities have over and over again been faced with being disregarded in their point of view or preference or viewed as incapable of making decisions or having opinions. As mental health practitioners it is important that we hold these understandings as we have conversations with persons with disabilities and challenge the ableist ideas of disabled lives, their sexuality, their agency and their ability.

In relation to disability and gender identity watch this talk at CLPR's Transform 2019 by Kiran Nayak B. where he talks about his disability, gender identity and his attempts to bring the two issues together in his work with his organisation Nisarga in a town in Karnataka. He speaks about how questions of gender and sexuality is not necessarily brought up in conversations about disability and LGBTQI conversations do not necessarily bring up disability. People exist at all these intersections. He speaks about the challenges of bringing all these conversations together and his attempts to build this intersectional movement as a trans, disabled person belonging to an indigenous community.

8. From the above readings and reflections, what are other things that stand out to you about keeping in mind

the intersectional framework when working with people with disabilities?



Zainab in the consultation interview for this manual said to Rising Flame:

"And then in my PG years, we have a part on women and law. So, there we will study specifically about feminism and how feminism has affected the law making and all and how conveniently the waves of feminism left out some section of woman, which includes disabled woman, which includes underprivileged women."

Though Zainab found resonance in feminism, she realised that historically waves of feminism had failed to take into consideration other marginalisations she experienced – being a Muslim woman and a woman with a disability.

Again and again persons with disabilities tell us that their experiences are not held in all their complexity. They tell us of the ways they are left out in their intersectional experience. Holding Mia's quote in mind at the start of this section about all the things that people need to understand to grasp her experience and the question she asks'l wonder what the things needed to hold your stories are?'

This is an invitation to think of this question every time we are in consultation with a new person. What are the things needed to hold stories? What discourses do we need to acknowledge? What privileges and world views do we need to examine? What 'expertise' do we need to unlearn? What understandings do we need to affirm? Whose experience and expertise needs to be honoured?



HOW MIGHT THESE REFLECTIONS ON INVISIBLE DISABILITIES AND INTERSECTIONALITY INFLUENCE THERAPEUTIC SPACES FOR PERSONS WITH DISABILITIES?



Believe their stories:

When people speak of stories of distress, marginalisation and discrimination, believe their stories. When people speak of experiencing distress, acknowledge the distress. Acknowledge that their experience is particular and seek to understand it better. Take an intentional, curious stance.

Support in identification of conditions:

Mental health practitioners may play a role in identification of conditions experienced – chronic illnesses, neurodivergence, other invisible conditions. This support may be crucial for people to feel seen and acknowledged in their difficulties and lived experiences. Support them to document their experience and offer your professional support in validating their experience. Offer other

lived experiences for people to find resonance in.

Support in self-advocacy:

Support people to identify their needs and assess their access needs. Support them to assess where they might disclose their disability and what support it might make possible. Support them in preparing for the vulnerability post disclosure, how can they take care of themselves post disclosure? What professional support can you offer so they have access to the accommodations they need?

Disability and Intersectionality informed therapeutic practices:

Consider if the practices you use are accessible and respectful of people with multiple marginalisations. Always acknowledge the systemic causes of distress. Consider that systemic discriminations and marginalisations affect sense of self, relationships, motivation, energy and mood. Do not internalise. Bring the systemic perspective to inform the internalised sense of failure or inadequacy.

Disability and Intersectionality informed safety planning:

In your safety planning practices, take into account gender, sexuality, caste and disability. When planning the steps to be taken, consider these aspects and plan accordingly. If they have high support needs, is living alone accessible? If they are queer, what spaces would be safe? If they are from a marginalised caste what spaces would be safe? What safety practices can be put in place within the home

when family spaces are not supportive of agency because of sexuality and/or disability?

Educate yourself:

Unlearn internalised explanations of distress, learn about systemic discriminations owing to caste, sexuality, origin, location, indigeneity. Learn about diverse lived experiences. Be tentative in your understandings and make space for people's lived experiences to dominate 'professional' expertise.





CLOSING NOTE

Understanding and exploring invisible disabilities and intersectionality of our experiences is an ongoing process – one we must persist on continuously to ensure we continue to unpack privileges, discrimination and the important aspects of challenging these structures within the therapeutic spaces we create.

We hope that these experiences, questions and reflections support your learning and unlearning of the complexities of invisible disabilities and intersectional understandings of disability. We propose these exercises as a start to this journey that will continue beyond the confines of this self-learning manual.

We hope the considerations of this manual invite you to centre the agency, expertise and experience of the persons with disabilities who consult with you in all their marginalisations.

Additional References

1) Purple People booklet: https://
https://
https://<a href="miss

Invisible Disabilities:

- 1. Video by Dawn Welters 'Audism:
 The silent microagression' from the
 Disability & Intersectionality Summit,
 2018 to learn more about the prejudices
 and assumptions of the hearing world.
- 2. Article on the experiences of women with schizophrenia at the workplace by Riddhi Dastidar titled 'Why workplace support is a basic need for women with schizophrenia' speaks about the challenges of disclosure with particular invisible conditions such as schizophrenia. The stigma and the prejudices surrounding certain conditions make it difficult to ask for access.
- 3. Video interview of Aditi
 Sowmyanarayanan on the Much Much
 Media show titled 'Non-speaking does
 NOT mean non-thinking'. Aditi speaks
 of some of the assumptions about
 non-speaking autistic people and the
 harm that it does to their access to
 communication and language amongst
 other things.
- 4. Book: Talking Fingers Voices of Indian non-speaking autistics.
- 5. This presentation of messages from authors of Talking Fingers: https://drive.google.com/file/d/1pjNCUhLSSkaD2yi24bMHLsttxS1HArfW/view
- 6. Bangalore PhD student on coming

out with Thalassemia in ORDI

- 7. <u>Real Stories from People Living</u> <u>with Thalassemia – Chanapa</u> <u>Tantibanchachai</u>
- 8. Multiple Sclerosis Society of India (MSSI) has **several videos and webinars on their YouTube channel** that raise awareness on the multiple facets of living with MS.

Intersectionality:

- 1. Interview of Dr. Aishwarya Rao with Greeshma Kuthar for no-niin titled 'Blending Art, friendship & Advocacy: A conversation with Dr. Aiswarya Rao
- 2. <u>FII Interviews: In conversation with Kiran Nayak. B, a trans, disabled, award winning social activist.</u>
- 3. Book: The trauma of caste: A Dalit Feminist meditation on Survivorship, Healing and Abolition by Tenmozhi Soundararajan
- 4. Disability and Intersectionality
 Summit has several talks from the
 North American context
- 5. <u>Diving into Disability Justice with</u>
 <u>Shivangi Agarwal</u>
- 6. <u>Disversations by Sappho for equality</u> In this video Dr Ranjita Biswas is in conversation with queer-trans* disability rights activists Nu, Ishaan and Suryatapa where they talk about finding and following love in an able-bodied world, far far away from the rules of able-bodiedness.
- 7. Book: Feminist, Queer, Crip by Alison Kafer





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www.risingflame.org

- https://www.facebook.com/risingflamenow/
- x https://twitter.com/risingflamenow
- https://www.youtube.com/@risingflamenow
- https://www.instagram.com/risingflamenow/