Holding Space

Deconstructing disability experiences and navigating ableism in therapeutic conversations - Part 1
Rising Flame is a nonprofit organisation based in India, working for recognition, protection, and promotion of human rights of People with Disabilities, particularly women and youth with disabilities. It is the Recipient for the National Award for Empowerment of Persons with Disabilities 2019. 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 a self-led organisation, 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. (Website: www.risingflame.org).

CREDITS
Concept: Nidhi Goyal
Author: Prathama Raghavan
Editor: Srinidhi Raghavan
Illustration and Design: Sonaksha Iyengar
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Image description of the front cover: Illustration of multiple people in a garden-walkway setting. The person on the bottom left is wearing a hijab and using a rollator walker as they move closer to join the group. On the bottom right corner are two people mid-laughter. They are both standing. The person on the right has curly hair which is tied in a bun on the top of their head. They are wearing a kurta and leggings with a dupatta. They are leaning against a pillar with one of their hands resting on it. They are wearing compression gloves and have kinesio taped their arm. The person on the left has short cropped hair and is wearing a patterned shirt with pants, with their hands behind them. They have a nasogastric tube connected through their nostrils. Behind them, a person is walking down the slope while holding a light brown dog with a leash. They have short cropped curly hair and are wearing a white tee shirt with an open purple flannel shirt and red pants. There are flowers growing behind them. There are stars of different sizes in the background, sparkling.
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Ableism and its effect of disabled people’s sense of self, their experiences of navigating the world
Introduction

This manual is the first part in a series of self-learning manuals for mental health practitioners, counsellors, therapists and persons providing mental health support facilities to persons with disabilities. This self learning manual will deconstruct the various nuances of ableism, its effects on disabled people’s lives in all their diversity and intersections centering the lived experiences of disabled people.

This manual with interactive elements and work sheets, is a tool to broaden your perspectives and a space to understand disability and experiences of disabled people and ableism. As you move through the next few pages, we hope you will nuance your understanding of disability and deconstruct ableism and learn to notice its tricks, games and dictates. We hope you will bring this understanding to your work with people both disabled and non-disabled.

WHERE DOES THE “PROBLEM” LIE?

As mental health workers we are taught to perceive disability in a particular way - as a ‘deficit’, as a ‘problem’, as people with disabilities having ‘special’ needs. As mere members of this society we are socialised to think of disability in a particular way - as something that is not OK, as something that should not exist, as something that is undesirable, unfortunate or divinely ordained. Why is that? Do you think these ideas come from the experience of living with a disability or from a non-disabled person’s perception of a disabled person’s life? What harm might it do to disabled people’s lives and sense of self?

Many of us — mental health workers provide care and support to those who live with disabilities. Do we end up reinforcing the very stereotypes that those who live with disabilities and disability activists want to steer us away from?

We invite you to engage with this manual in honesty and with a curiosity to learn and unlearn and in the process be better, more accountable mental health care providers to people living with disabilities and allies to the disability community.

Ableism is all around us and invariably all of us have been influenced by it, become agents of it — both those of us who are disabled and
non-disabled. This manual has the intention of making its operations and its effects on people’s lives more visible. It is not to shift blame on ourselves or others but to be more aware of ableism in our lives, in society and in the lives of people around us.

The exercises, activities and worksheets in this manual are designed for self-learning, they can also be used in workshops and trainings as a guide to build disability related sensibilities of counsellors and therapists for the future. This manual is rich with the work and wisdom of people with disabilities from India and the world. We hope you relish it as much as we did in putting it together.

We use the words disabled person* or person with a disability** interchangeably. You will discover as you go through the manual the intentions and stance of using these particular words. The ideas discussed in this manual are applicable to people with all kinds of disabilities, people with chronic pain and illnesses, developmental disabilities, the neurodivergent community and the deaf community.

* Disabled person is an example of identity first language which was reclaimed by disabled people as an affirmation of the social model of disability — as in being disabled by the social and environmental contexts rather than by the conditions they experience.

** Person with a disability is an example of person first language which is a linguistic movement that became popular in the late 80’s in the US with the intention of putting the person first, or seeing the person and not the disability. It was critiqued by some disability communities who preferred identity first language. Some disability communities felt it implied shame or something to hide instead of true equality. However some disability communities prefer person first language.

Person-centered language refers to using the language the person being referred to is comfortable with, for example many people in the autistic and deaf community prefer autistic person or deaf person however there may be people with other disabilities who might prefer person with a disability.
Think about these questions and write down your answers.

Keep coming back to these questions as you navigate this manual and observe if your answers are different.

1. What image comes to your mind when you think of a disabled person?

2. When you read the words ‘disabled people’ what is your opinion about it? Did it sound ok to you? Or not OK? Did you think it lacks respect for people with disabilities? Does disability or disabled feel like a bad word? Why do you think that it is?

3. Do you wish we’d used other words instead? What are those?

Let’s think a bit more about this...

4. What words come to your mind when you think of the word ability?

5. What words come to your mind when you think of the word disability?

6. How are the words ability, disability or even inability used in common language? What words are used for these in other languages you speak?

7. What do the words ‘independence’, ‘productivity’ and ‘functional’ evoke for you when used to describe human lives?

8. What might a disabled person look like?
We’d like you to consider some words on dependence and independence from an essay by activist, writer and speaker focussing on disability issues - Cal Montogomery called ‘Critic of the Dawn’ as you start your way through this manual.

REFERENCE:
Cal Montogomery — Critic of the Dawn

Independent can mean self-governing. It can also mean self-reliant. It can deny others’ influence on our decisions or others’ support in carrying those decisions out.

Dependent can mean controlled by others. It can also mean requiring the support of others.

None of us of course is independent in either sense. We grow up in social contexts, supported and denied, enabled and disabled by those around us.
Some rely on supports which is so common as to go unnoticed, while others use support that is atypical and therefore apparent. Some supports are provided by the community as a whole and go unnoticed while others are borne — or not — by a small number of people whose lives are profoundly affected.

Disability on this understanding is not in-ability but dis-enablement, and non-disabled people are not in comparison to us innately able. They are rather, enabled by a society set up to accommodate their needs not ours. Disability is injustice, not tragedy; unequal treatment not inherent inequality.
We leave you with some words by Mia Mingus, a writer, educator and trainer for transformative justice and disability justice.

REFERENCE: Mia Mingus - Access Intimacy, Interdependence and Disability Justice

Understanding disability and ableism is the work of every revolutionary, activist and organizer—of every human being. Disability is one of the most organic and human experiences on the planet. We are all aging, we are all living in polluted and toxic conditions and the level of violence currently in the world should be enough for all of us to care more about disability and ableism.
Disabled people get told we must shrink ourselves and our desires to settle for living in the wake of an able bodied parade. And especially if we are part of other oppressed communities, we are expected to be grateful for whatever crumbs are thrown our way.

It is easy to list these things off and analyze them, but it is harder to convey the way they have felt. It is harder to talk about how incredibly—sometimes unbelievably—painful these have felt when experienced.
SECTION 1

Deconstructing Ableism

1. A. WHAT IS ABLEISM?

1. Before we go on to read some definitions of ableism — what comes to your mind when you think of ableism? What might it look like?

2. What are some situations where you might have noticed ableism? Or situations people who consult with you have might have mentioned that could be dominated by ableism?

Definitions:

ABLEISM
[a·ble·ism] noun.

✧ Ableism is the discrimination of and social prejudice against people with disabilities based on the belief that typical abilities are superior. At its heart, ableism is rooted in the assumption that disabled people require ‘fixing’ and defines people by their disability. Like racism and sexism*, ableism classifies entire groups of people as ‘less than,’ and includes harmful stereotypes, misconceptions, and generalizations of people with disabilities.

REFERENCE: Ashley Eisenmenger - Ableism 101: What it is, what it looks like, and what we can do to to fix it

✧ A system that places value on people’s bodies and minds based on societally constructed ideas of normalcy, intelligence, excellence and productivity. These constructed ideas are deeply rooted in anti-Blackness, eugenics, colonialism and capitalism*.
This form of systemic oppression leads to people and society determining who is valuable and worthy based on a person’s appearance and/or their ability to satisfactorily [re]produce, excel and “behave.” You do not have to be disabled to experience ableism.

A working definition by Talila “TL” Lewis in conversation with Disabled Black and other negatively racialized folk, especially Dustin Gibson; updated January 2020.

REFERENCE: Talila “TL” Lewis - Ableism 2020 - An updated definition

* FOOTNOTES

* And Casteism in Indian and some other South Asian cultures and histories and normative ideas of gender and sexuality.
3. What do these definitions of ableism bring our attention to?

4. When you look back at your answers to the questions in the introduction about disability and ability — would you consider any of the words you used to be ableist now? Which ones and why?

5. What do you think are the possible effects on ableism on people?

6. What is understood as ‘normal’?

7. How do these ideas of ‘normal’ or ‘typical’ influence our perception of persons with disabilities?

8. How might this change how we perceive their know-hows and skills, their talent and potential?

9. “This form of systemic oppression leads to people and society determining who is valuable and worthy based on a person’s appearance and/or their ability to satisfactorily [re]produce, excel and “behave.” How might this influence a disabled person’s mental health?

10. In Talila “TL” Lewis’s definition, they say “You do not have to be disabled to experience ableism.” How might ableist ideas of ‘(re)produce, excel and “behave” dominate non-disabled lives too? What effects might they have? Can you think of ways that these ideas restrict our ways of being?

11. What is your understanding of ableism from these definitions and reflections — what words would you use to explain it to someone else?
Notes on ableism

Ableism is really all around us, in our ideas of productivity and achievement, in our ideas of a life worth living, in our ideas of being ‘broken’ in the ideas of ‘normal’ and ‘abnormal’ in our ideas of who can be ‘employed’, who can make choices and decisions, who is considered ‘competent’ or ‘trustworthy’.

I experience ableism everyday, and it is directly related to my disability, gender and sexuality. It impacts my career as I mostly receive rejections from jobs.

It also impacts my relationships as friends or family are unwilling to accommodate my body.

But most of all it impacts my community, as we don’t have access to the most basic social, economic, education and housing rights.

SHIVANGI AGRAWAL

Image description: Shivangi Agrawal standing with a yellow decorative background with red stars. There is a red and pink flair next to their face. Shivangi has short and curly hair.

They have tattoos on their neck and shoulder. They are wearing a strappy denim dress, large square glasses and pink lipstick. They have a nosepin, a septum ring and are wearing earrings.
All those of us who studied psychology inevitably had a paper or topic on ‘abnormal’ psychology. When we frame lives in the binary of ‘normal’ and ‘abnormal’, ‘high functioning’ and ‘low functioning’, the ideas of ‘dysfunction’ and its relation to ideas of ‘impaired functioning’, we categorise people’s worth, the worth of their lives and experiences. We enact these categories by providing for the needs of some people and their comfort as routine and making the needs of others, those Ableism deems ‘abnormal’ or ‘low functioning’ as optional or ‘special’. As one woman with a disability said it leads to ‘accommodations seen as an advantage’ as if ‘they are doing a favour’. When we teach language for communication to children we do not consider it an accommodation. Why then do we consider teaching sign language or braille or using of screen readers* as ‘special’ needs? Aren’t they just options to spoken and written language?

Ableism affects people’s sense of self causing them to feel unworthy, as a ‘burden’ to their families and societies, as ‘not enough’ or as ‘failures’. Ableism leads to us demanding that disabled people try hard to look ‘normal’, to navigate a world that is not supporting their needs through ‘hard work’ or ‘masking’ (acting ‘normal’). Instead of placing the responsibility on society to make spaces and information accessible to everyone — ableism places the responsibility on disabled

*FOOTNOTES

* A screen reader is a form of assistive technology (AT) that renders text and image content as speech or braille output. Screen readers are essential to people who are blind, and are useful to people who are visually impaired, do not read, or have a learning disability. Screen readers are software applications that attempt to convey what people with ‘normal’ eyesight see on a display to their users via non-visual means, like text-to-speech, sound icons, or a Braille device. (Wikipedia)
people to learn or ‘adapt’ to the ways society has chosen to organize itself favouring non-disabled people.

As Nidhi Goyal, disability rights and gender justice activist, founder and executive director of Rising Flame and comedian says in an interview on ‘Charcha-Cast’ with US Consulate Mumbai, if a training was organized on the 75th floor of a building without an elevator would you go? You just have to work hard to get to the 75th floor. That is not expected out of you by society but it would be expected of a person using a wheelchair or crutches. Imagine how much harder it is for a wheel-chair user to access activities that are routine for non-disabled people — taking a stroll on the street, going to a coffee shop or restaurant, going to a language class or an art class if the buildings are not designed for wheel chair users. If buildings, language teaching and technology to name a few things were adapted to the diversity of human beings instead of non-disabled people alone then would these needs be ‘special’?

People are disabled not by their bodies or minds or abilities but by an intentional negligence of society to take their needs into the design of society. Ableism has led society to construct itself for the needs of some people and not others, thus disabling some members of society, leading to us treating some people as ‘less than’, as ‘less able’, as needing support or as people having to overcome great odds that society has created for them. As if all members of society have not needed and accessed support every day to get from one place to another, to read, to write, to communicate, to learn, etc. and as if it would be considered a great achievement if non-disabled people just got from one place to another and learnt to communicate and navigate the world. Both these extremes are influenced by ableism and absolves the responsibility of society to make itself accessible to the diversity of the human experience.

1. B. WHAT DOES ABLEISM LOOK LIKE IN THE EVERYDAY FOR PEOPLE WITH DISABILITIES?

Watch this TEDx Talk at Amity University by Disability Rights & Gender Justice Activist, Founder and Executive director of Rising Flame and Comedian - Nidhi Goyal

Please read the questions 1 and 2 below before watching or listening to the talk.

1. As you watch the talk, note down the everyday experiences of ableism that Nidhi Goyal brings attention to.
2. What are some misconceptions and cultural notions of disability Nidhi speaks about?

3. How might these ideas influence a disabled person’s experience of the world?

4. Nidhi Goyal says ‘We either look at them from the pity lens or the inspirational lens.’
   - What are some examples of ‘pity lens’ thinking that Nidhi Goyal mentions in her talk?
   - What are some examples of ‘inspirational lens’ thinking that she mentions in her talk?

5. How do these beliefs influence how we perceive, behave and respond to people with disabilities? Do these beliefs cause harm to the disability community? If so, how?

People with disabilities are often portrayed as comic reliefs of sort where you can feel good about yourself by feeling bad about them. So that’s the kind of space where we want others to take inspiration from. This sort of stereotype not only maligns the kind of perception people with disabilities want of them-selves but also prohibits any sort of inclusiveness. This also means we cannot learn from each others’ experiences or even acknowledge our very different experiences.

NIYAR SAIKIA

Image description: Niyar Saikia is standing against a pink background of colourful flowers with white decorative designs. Her arm is lifted and she is smiling. She has long hair that is open. She is dressed in a black sleeveless top. She has glasses on her forehead and is carrying a brown sling bag.
Notes

The ‘pity lens’ and the ‘inspirational lens’ contribute to what is called the ‘charity model of disability’. ‘According to the Charity Model of disability, a person has a disability. This disability is a ‘problem’ in their body and good citizens should feel pity for the disabled person’s tragedy, or be inspired by a disabled person’s achievements.’

REFERENCE: Nim Ralph - Understanding Disability: Part 4 — The Charity Model

The ‘charity model’ of disability sees people with disability as in need of ‘help’, unable to do things for themselves. While many charities offer vital support, a lot of these fundraising and efforts emphasized the helplessness of people with disability and risked undermining their autonomy, independence and rights. It is a model often adopted by mainstream media.

REFERENCE: Disability Advocacy Resource Unity: Shifting models of thinking

6. Nidhi says there is this surprise people experience with her as a blind woman laughing. Why do you think that is? What ideas perpetuated by ableism does this bring our attention to? What images come to your mind when you think of a blind person?

7. She speaks about the notions of people with disabilities as ‘inspiring memes or depressed individuals — they are either super human or less than human beings — not ‘normal’ - someone who is that other’. What effect might these perceptions have on a person’s mental health?
Image description of illustration on Page 18: Two people mid laughter. They are both standing. The person on the left has curly hair which is tied in a bun on the top of their head. They are wearing a kurta and leggings with a dupatta. They are leaning against a table with one of their hands resting on it. They are wearing compression gloves and have kinesio taped their arm. The person on the right has short cropped hair and is wearing a patterned shirt with pants, with their hands behind them. They have a nasogastric tube connected through their nostrils.
In a poignant talk as part of the Point of View Series — Pyaar Plus - Parvathy Gopakumar, a law student and a nemophilist talks about the effect that these ideas had on her mental health. She says she acquired a disability following an accident when she was 12 years old.

REFERENCE: Parvathy Gopakumar — My journey, a video part of a series Pyaar Plus by Point of View

I pretended to be happy and confident and people around me were actually complimenting me for taking my disability so lightly, that my parents aren’t stressed. So I came to the conclusion that my parents’ happiness solely depended on how I tackled things... I was hell bent on faking all happiness and confidence because I didn’t want anyone especially my parents to know what I was really going through — I was really hard on myself...All of this while I was constantly comparing myself to others.

I remember taking great pride in not crying in front of others — although I used to have these terrible breakdowns when I was alone or in the washrooms or something.

PARVATHY GOPAKUMAR

Image description: Illustration of two quotation marks, stacked. The open quotation mark on top is red and has pink dots outlining it and the closing quotation mark on the bottom is yellow and has orange dots outlining it.
Priyangee Guha, a human rights lawyer who is autistic speaks about the ex-haustion of ‘masking’ (acting non-autistic) that is the reality for many autistic people who have to navigate a neurotypical world everyday.

REFERENCE: Priyangee Guha in Honoring Helen Keller by Understanding Disability: An event organised by Rising Flame and US Consulate in Mumbai

I somehow, I have no idea how, but I managed to pass 1 class after the other, 1 degree after the other. I’m 10 years into the profession. When you see my profile, you see, a person who has achieved a lot of things. You see my degrees, my work experience, I’m usually a lot more humble person, but you know what I’m trying to say here. But what you do not see is the amount of effort I have to put as per rules that are not conducive to who I am. You are not seeing the effect it has on my health. You do not see the anxiety that this brings, rules and conditions bring in. After 8 hours of school or work, after 3 hours of homework, etc. I need 12 hours of sleep, to simply have energy to live. Why? Why is that? Because simply existing as per your rules is exhausting.

Acting like I’m normal so I don’t get bullied is exhausting. Like Nidhi said, I want access to all the things that a non-autistic person has, and for that I have to pretend that I’m non-autistic, so that teachers don’t come and tell my parents that it is not my responsibility to handle her. And in order to get the same amount of access to do well in life, I need to pretend that I’m non-autistic and that is exhausting. All this because, the system refuses to acknowledge our existence, let alone provide us with support.

PRIYANGEE GUHA
When people see me, they don’t see a disabled person. Because I am probably laughing loudly and my laughter must mean that my invisible disability is not real. Trust me, when I say I am disabled. Trust me, without demanding I share intimate medical information as evidence, as proof that these conditions impact my being. This disbelief that I cannot be happy and disabled or that you need to see my pain to believe me is ableism.

SRINIDHI RAGHAVAN on ableism
8. Nidhi goes on to talk about Sexuality and women with disabilities — what does this bring attention to in terms of how society perceives sexuality and sexual and reproductive rights of women with disabilities? How does this differ from sexual and reproductive rights of non-disabled women?

**FURTHER REFERENCE:** Watch the documentary AccSex which talks to women with disabilities and their navigation of sexuality

9. At the end of her talk Nidhi speaks about how ‘Disability doesn’t stop us from having experiences, from living a full life. What does, is the environment. What stops us, is the attitude of people around us.’

What are some things in the following contexts that come in the way of disabled people living a full life? How does ableism show up in these contexts?

- Education system
- Family relationships
- Intimate or romantic relationships
- Friendships
- Work

10. What effect do these barriers in the environment have on a disabled person’s sense of self or their perception of their skills? How might they view themselves as a result?

**Notes**

The effects of ableism on a person’s perception of their skills, their sense of self is pervasive, painful and exhausting. It results in people doubting themselves, wondering if they are asking for too much, being ashamed of having access needs, isolating themselves, not seeking support, constantly questioning themselves, their worth and right to be a part of experiences and spaces.

When speaking of effects of ableism they experience on their lives in various spheres of life, women with disabilities spoke about many different things illustrated in quotes below. As you read these quotes consider what effects it might have on their mental health and sense of self if these things they mention happen repeatedly and in every situation.

“Not being marriageable — disabled people are assumed to not care for themselves and others, therefore we cannot be married”

“There are ramps, they say but there are some steps — they don’t realise that even one step is a barrier” for someone who is a wheelchair user or uses crutches.

A woman who experiences a speech disability said “Asking somebody to talk for me or asking me to talk louder”
“I have to think how to reduce their problem when someone is helping me for example my mom or a caregiver”

“ Asking me as a blind person to present from a laptop already set up which might not have the accessibility features needed to use the powerpoint” as opposed to presenting perhaps from her own laptop or making sure the laptop set up had the accessibility features needed and was comfortable to the person presenting.

In Priyangee’s quote above she speaks of the influence of Ableism on accessing education, the exhaustion of having to act ‘normal’ or non-autistic in order to have access to the same things as a non-autistic person. Another woman with disability speaking about her experience at the workplace spoke about how she was told “You are exempted from meetings on the second floor because it is not accessible.” Instead of finding a way to make the meeting accessible to her as a valued member of the team.

11. Women with disabilities mentioned these things amongst many others listed below as how ableism shows up in their relationships, work or education environments and public spaces in workshops conducted by Rising Flame over the years.

Read them carefully first.
What does it get you thinking about what assumptions you have of what disabled people can or cannot do?

How might it come in the way of supporting their mental health as a mental health worker? What are some steps you might take to become more aware of these assumptions?

✧ You are exempted from meetings on the second floor because it is not accessible - a woman with locomotor disability

✧ Asking somebody to talk for me or asking me to talk louder. This is annoying and hurtful - a woman with speech disability

✧ I have to think how to reduce the problems of my caregiver when they are helping me - a woman with locomotor disability

✧ Giving me administrative roles because they don’t trust that I will be able to do the tasks they had hired me for. I tried to protest once or twice and then gave up - a blind woman

✧ As a person with disability, I am always responsible. The non-disabled person never takes responsibility to make spaces and systems accessible for people like me - a disabled woman
Notes

Here is a quote by Mia Mingus about the effects of ableism in disabled people’s lives. Mia Mingus, is a writer, educator and trainer for transformative justice and disability justice. She is a queer physically disabled Korean transracial and transnational adoptee raised in the Caribbean.

I have watched ableism tear apart relationships with people I love. I have seen access be too much of a barrier for people to be in relationship with each other. I have made excuses for inaccessibility because I loved people and didn’t want to lose relationship with them. I have excused racism, sexism, violence, homophobia because I didn’t want to, couldn’t afford to, lose access. I have asked for access or raised ableism in relationships, only to have those relationships end abruptly. I have stayed in relationships for access and I have been too afraid to enter into relationships because of access. I have had access held over my head, leveraged for able-bodied supremacist means, or treated like a reward for good behaviour. I have had access made invisible or belittled by loved ones; I have had to make access happen so the person providing access didn’t know they were. I have kept parts of myself from people I love because I was afraid to, didn’t know how to, be whole and complex in the context of needing access.

This is the cruelty of ableism: it robs us from each other. This is the weight of access. This is what gets said in whispers, not on the microphone and at the panel. This is what gets shared in a fleeting glance between us, disabled, sick, crip folks; a recognition, a silent sigh, an unfocused stare. This is what we don’t share, don’t know how to share, because it is
so instinctual, so ground-level, so what’s-the-point-it’s-never-going-to-change. This is the air I’ve breathed since I can remember, as a disabled child, never knowing it could be any different—never having been able bodied.

Mia’s quote gets us thinking about why it is important for everyone to be informed about disability and access, the harm and damage that ignorance does to disabled people’s lives cannot be neglected.

We each have a responsibility to make ourselves informed, read and learn from experiences of the disability community and be more and more accountable in our actions. This is really not optional.

REFERENCE: Mia Mingus - Access Intimacy, Interdependence and Disability Justice
1. C. DELVING INTO THE INSPIRATIONAL LENS AND THE SOCIAL MODEL OF DISABILITY

Watch this TED talk by Stella Young, comedian and journalist who goes about her day in a wheelchair —titled ‘I am not your inspiration. Thank you very much’.

Note: Please read question 1 before watching or listening to the talk.

1. What stands out to you from Stella Young’s talk about how ‘disabled people are viewed or represented as objects of inspiration’ in our societies? What images, movie scenes or conversations you have heard about disabled people speaks to this idea of disabled people as inspirations?

2. She says ‘We have been sold the lie that Disability is a Bad Thing and living with disability makes you exceptional.’ What does this line evoke for you? Do you agree with Stella?

3. How does the idea that disability is a bad thing influence how disabled people’s skills are perceived? How might this affect the skills and training that are made available to disabled communities?

4. Do you see a connection between the idea of ‘disabled person as inspiration’ that Stella Young speaks about and the idea of ‘disabled person as other’ that Nidhi Goyal mentions in her talk? What connections do you see?

5. Stella talks about using the term ‘disabled people’ deliberately. She subscribes to the social model of disability which tells us that ‘we are more disabled by the society that we live in than by our bodies and our diagnoses’ contrasted with the medical model of disability*. What does thinking about disabled people through this lens make possible, you think?

6. When you look back at the experiences of disabled women mentioned earlier — what does it get you thinking about the importance of environments being accessible for disabled people? What influence might it have on their mental health?
7. Stella Young talks about the quote ‘The only disability in life is a bad attitude’ and it not being true and the focus on ‘disabled people as inspiration’. Reflecting on that how does this inspirational lens contribute to what actions may or may not be taken to make environments and experiences more accessible? Have you any references or examples of how this happens?

*FOOTNOTES*

* The social model of disability is a way of viewing the world, developed by people with disability. The social model of disability says that people are disabled by barriers in society, such as buildings not having a ramp or accessible toilets, or people’s attitudes, like assuming people with disability can’t do certain things.

The medical model of disability says people are disabled by their impairments or differences, and looks at what is ‘wrong’ with the person, not what the person needs. We believe that the medical model of disability creates low expectations and leads to people losing independence, choice and control in their lives.

SOURCE: Australian Federation of Disability Rights Organisations - Social Model of Disability.
Notes
As mentioned in the notes sections before and as illustrated by the various quotes of persons with disabilities throughout this manual, in the talks by Nidhi Goyal and Stella Young — looking at people with disabilities through the ‘inspirational’ lens or the ‘pity’ lens has real life consequences on what society does, on what responsibility society takes to make systems and spaces accessible to the diversity that exists in the society. Both the ‘inspirational’ and ‘pity’ lens based on the medical and charity models of disability discussed above make the hard work of disabled people or the ‘help’ of non-disabled people the centre of the societal response, thus placing the problem in the person and not making spaces and systems accessible by design and intention.

Nidhi Goyal says in her interview on Charcha-cast, a series of videos made by US Consulate Mumbai: “Disabled people are either ‘incapable’, ‘depressed’ and ‘defective’ or they are these superheroes — I can be one of two — when I’m ‘inferior’, ‘less’, ‘defective’ or ‘depressed’ the automatic ‘normal’ is the non-disabled person who could then really ‘help’ this ‘poor’ person.”

She goes on to say “Once we say this person is really strong and they triumphed over everything — they are able to battle everything and overcome everything then the responsibility shifts from us — then we don’t have to make spaces accessible, we don’t have to make systems accessible.”

REFERENCE: Charcha-Cast Ep.2 — Interview with Nidhi Goyal

Norman Kunç — Disability Rights and Inclusive Education advocate speaks about ‘The Right to be disabled’ and ‘Relocating the problem of disability’ in this video.

He speaks about using the phrase ‘The right to be disabled’ in a conversation with his friends. He says “At that moment my life changed. Prior to that night I’d seen disability solely as something within my body. It was an abnormality, a deficiency. But that night what I suddenly realised was I had a people. And I saw disability rather than in a physiological context, in a social context.” He speaks about recognising that there had always been people with disabilities in the world, in every civilisation, culture and society. He says “What I think I realised in that moment was that I was part of the normal diversity of the human community.” He quotes John McKnight who worked along the civil rights movement “Revolutions begin when people who are defined as problem achieve the power to redefine the problem.” In this context, this would mean the ‘problem’ of the disabled person redefined as the problem of an ableist society. Relocating the problem of disability
means “we go from the presumption that people should not be disabled to the idea that disability is an inherent part of the human experience.” This is crucial in our understanding of disability through the social model and the advocacy for access and design for all. He explains further by saying “So that ramp rather than being an accommodation for me is the correction of an architectural error.” The correction of an architectural error — looking at access in this way — places the responsibility on society to make spaces and systems accessible to everyone and leave no one behind.

Norman Kunc and Emma Van Der Klift have a wealth of resources on disability and inclusive education on their page.

8. Let’s think a little about where we are at. What has become more visible to you regarding the dictates of ableism and its effects on people’s lives? What tricks and tactics that you can use has become visible to you to resist ableism?
1.D. INFLUENCE OF ABLEISM ON LANGUAGE

1. The term ‘special needs’ is often used to refer to the access needs or supports that disabled people need. How is this term influenced by ableism? By calling these access needs ‘special’ — what is being suggested?

2. Would requiring glasses be a special need? Would requiring an interpreter when in a region that speaks a different language be a special need? What are considered as special needs then? How do you notice the influence of ableism on this term?

3. ‘Special Education’, ‘Special schools’, ‘Special children’ are other ways this term ‘special needs’ shows up in language around disability. What influence of ableism on our society does this language reveal?

4. Do you think the use of the term “special” contributes to perceiving disabled people as ‘the other’ that Nidhi Goyal talks about in her TED talk?
Notes

‘The ‘medical model’ of disability focuses on the person’s impairment or physical or mental medical condition and regards the person as the ‘problem’ and unable to do certain things. This thinking has been fundamental in approaches like sending children to ‘special’ schools or employing people with disability only in sheltered workshops.’

SOURCE: Disability Advocacy Resource Unity: Shifting models of thinking

It gets us thinking about who decides what needs are ‘special’ and what needs are ‘routine’. We are all of us dependent on entire communities of people growing our food, processing it, packaging it, transporting it, selling it, to be able to eat our meals and yet this dependence is routine, but needing a ramp or a wheel chair or a sign language interpreter or a scribe or longer time to write or read is ‘special’. If disabled people point out these needs or these barriers ‘we are perceived as causing trouble’ a woman with a disability said when asked about ableism’s influence. There are some alternatives that are being used to the language of ‘special needs’:

Image description: Illustration of two people from above with their arms wrapped around each other’s arms and their faces visible. One of them is a person with wavy hair tied in a low bun. They are wearing a top with frilly trims around the sleeves. The other person has short cropped hair and a french beard. They are wearing a buttoned tee shirt. There are swirly waves or spirals in motion in the space between them. There are lots of arms reaching out to form a network of support around both of them on either side.
Universal Design — “Universal Design is the design and composition of an environment so that it can be accessed, understood and used to the greatest extent possible by all people regardless of their age, size, ability or disability.”

**REFERENCE: National Disability Authority - What is Universal Design**

The Universal Design for Learning - Universal Design for Learning (UDL) is a framework to improve and optimize teaching and learning for all people based on scientific insights into how humans learn.

**REFERENCE: CAST: Universal design for learning**

Inclusive Education — Norman Kunc maintains that inclusive education is not simply something we “do” to students with disabilities, but involves a school making an intentional commitment to build and maintain a sense of belonging for all students and adults in the school.

**REFERENCE: Broadrech Training and Resources - Inclusive Education**

Inclusive Access Arrangements — A term used by the International Baccalau-reate (IB) education programs. ‘Standard assessment conditions may put some candidates at a disadvantage by preventing them from demonstrating their level of attainment. Inclusive access arrangements may be applied in these circumstances if it is observed that they could reduce or minimize barriers for the candidate.

Inclusive access arrangements may be necessary due to:

- long-term learning support requirements
- temporary medical conditions
- additional language learning.

**REFERENCE: IB Access and Inclusion Policy**

5. What about the phrase ‘differently abled’ frequently used instead of disabled — what influence does the use of this term reveal on what society thinks about disability? Might it suggest we think it’s a ‘bad thing’ as Stella Young says? If yes, how?

**Notes**

Disabled persons and communities in different contexts may choose to use any of these terms themselves. Respecting their preference is important in respecting their agency. The above-mentioned influences on language are important to understand that ableism influences language and hold this awareness close as we navigate the language that is used in speaking about disability. It is not meant for correcting persons with disabilities use of language for themselves or their communities. It is always best
to use the language that the person themselves is using while intentionally relocating the problem of access in ableism and an inaccessible world rather than in the person with disability.

In the spirit of unpacking a little further ableism’s effect on language — let’s think about the words disabled and ‘differently — abled’, using ‘differently-abled’ once again implies that the problem is within the person and uses a eu-phemism* to imply ‘let’s not look only at their problem’. Only being the key word. Differently abled simply suggests that they have skills other than the ‘problem’. But it still places the problem within the person. Whereas disabled according to the social model of disability as described by disabled people themselves points out that a person is disabled by the lack of access and atti-tudes of society and that disabled people are an inherent part of the diversity of the human experience.

6. There is ableist language in our everyday vocabulary. See below lists of words, phrases or statements that are ableist. Write out the other ways in which these words/statements can be phrased without ableist language. Do your own research if needed, about alternatives to these words.

7. Is there something that you would like more information on? Find articles, videos and resources on the internet related to a particular idea discussed above that you want to find more information on.

* FOOTNOTES

* A polite expression used in place of words or phrases that might otherwise be considered harsh or unpleasant
GROUP 1

✧ Retarded
✧ Stupid/Dumb/Idiot/Imbecile
✧ Handicapped
✧ “I’m so OCD”
✧ “That politician is such a sociopath/psychopath”
✧ “If I ever became disabled, I’d just have them pull the plug”

GROUP 2

✧ Crazy
✧ “Deaf, dumb, and blind”
✧ “The weather is so bipolar”
✧ “Lol are you triggered?”
✧ “Wow you got to park so close! I wish I could use handicap parking”
✧ “If you could cure your disability/disease, would you?”
Instead of these Ableist Words/Phrases, Use these alternatives:

_____ is so **Bipolar**

Erratic, All over the place, Unreasonable, Back and Forth

**Lame**

Bad, Awful, Gross, Uncool, Cheesy, Tacky, Corny

I’m so **OCD**

Meticulous, Neat, Picky

**Spaz, Retarded**

Silly, Dorky, Cheesy, Nonsensical, Illogical

**Stupid, Retarded**

Frustrating, Pointless, Annoying, Perplexing, Irritating, Obnoxious, Confusing, Foolish, Silly

_____ is making me depressed

Upset, Sad, Blue, Disappointed

**Crazy, Insane, Mental**

Unreasonable, Absurd, Outrageous, Unacceptable, Ridiculous, Unreal, Unbelievable, wild, confusing, unpredictable, impulsive, reckless, fearless, lives on the edge,

thrill-seeker, risk-taker, out of control

**Psycho, Sociopath, Psychotic**

Dangerous, Menacing, Threatening, Evil, Murdering, Strange, Criminal

**Deaf to, Blind to**

willfully ignorant, deliberately ignoring, turning their back on, overcome by prejudice, doubly anonymous, had every reason to know, feigned ignorance

**Dumb**

dense, ignorant, lacks understanding, impulsive, risk-taker, uninformed, silly, foolish (to replace metaphor); nonspeaking, nonverbal, person with a speech impairment, person with a cognitive disability, Deaf person, hard of hearing person (to refer to a Deaf or disabled person)

Some further reading on intersectional understanding of disability:

**MIA MINGUS:** ‘Disability Justice is simply another term for love’

**SRINIDHI RAGHAVAN:** ‘To challenge ableism that manifests in Social Justice movement — Intersectional understanding of Disability is vital’
Don’t mourn for us
by Aishwarya Othena from her blog ‘Sight Unseen’

Don’t mourn for us
Pitiful cripples we might be in your eyes
But mine, although unseeing, can see past your prejudices to our wonderful lives
Don’t mourn for us
Or the fact that there aren’t any “cures”
We are not broken, and do not need to change to fit those molds of yours
Don’t mourn for us
It is you who have never bothered to get to know us, and our reality
Before categorizing our lives as “not worth living” without being brought back to normality
Don’t mourn for us
Because disability is so much more than what you have bothered to see
It is a way of being, an experience, an aspect of our identity
Don’t mourn for us
Because the tragedy is not that we’re here
The tragedy is that your world is not built for people like us to experience without fear
Don’t mourn for us
Instead, be an ally, a supporter
But be warned, to join us you will first have to be an un-learner
SECTION 2

Ableism and its effect of disabled people’s sense of self, their experiences of navigating the world

“Ignorance ceases to be an excuse, curiosity is irritating. Help against my choice is absolutely not welcome” — Nidhi Goyal

REFERENCE: Nidhi Goyal
- Tedx Amity University

In addition to the pity lens and inspirational lens — ignorance, curiosity, help without consent and discrimination based on all of these are aspects of ableism that have real effects on the lives of persons with disabilities. They might bring guilt or shame about needing ‘too much’ help or needing certain access arrangements to do things with friends or family — not being able to do some things. Shame brings blame, ableism telling disabled persons that they should not need these things, shame, blame and guilt bring thoughts or feelings of ‘not being good enough’, ‘not doing enough’, if I only adopted the ‘I can do this’ attitude — everything is possible’, ‘everything is possible if I try hard’. Through many tasks and navigating many spaces, since they were young children to when they become adults — these effects of ableism have been oppressing them. As Mia Mingus says in the quote mentioned above

they should adjust or adapt — for this one time — “I should let it go”, “they are doing so much for me” “I shouldn’t complain” “It is my fault, people can’t meet all my needs, I have so many” “They must have forgotten” “They must not mean it” “I am asking for too much” “I don’t want to ask this again, I just won’t go, I just won’t do it, I’ll try hard to do it by myself”.
“This is the cruelty of ableism: it robs us from each other... This is what we don’t share, don’t know how to share, because it is so instinctual, so ground-level, so what’s-the-point-it’s-never-going-to-change. This is the air I’ve breathed since I can remember, as a disabled child, never knowing it could be any different—never having been able bodied.”

What is standing out to you as the ‘cruelty of ableism’ from the things you have read, listened to and thought about so far?
ON GUILT

Srishti Pandey in this ‘Lightning Talk’ titled ‘Friends, Conditions Apply’ part of a Rising Flame series — talks about the guilt and how it influences friendships and her own behaviours “most of the time the guilt of having friends who are extremely supportive overpowers the feelings of being lucky or grateful’ for her. She talks about experiences she had in school and realizing only later that friends used her disability for their benefit — to seem like a good student to the teacher or to find an excuse for doing homework or escape punishment. She says “Whenever they would try to use me I would tell myself that maybe that’s ok, maybe I owe them this much”. She goes on to say “On most days I would feel like a burden. My brain would sideline all the favours I had done for them and only focus on favours I had received. So I started offering them extra help — doing their homework, or sharing my notes. I started putting their needs over mine.”

ON SUPPORT AND CONSENT

“Either I need help all the time or I do not need help at all. Either I can walk all the time or I can’t walk at all. There are things I can do on my own like eating food or cracking bad jokes.”

Kavya Mukhija in her ‘Lightning Talk’ titled “Consent & Daily Living” part of a Rising Flame series talks about consent in daily living. She asks ‘Is consent in daily living really consent or does it fade away as time ticks by?’ She talks about the complications of consent in the lives of persons with disabilities who need physical touches from others in their daily routine “while bathing, while wearing clothes, while lying on the bed, etc.” She says “It is something all of us present here won’t allow without proper consent.” “Without them (my parents) helping me out, I won’t be able to bathe or do the other things by myself, so we have unspoken norms in mind.” She says that when “we get so used to going on with the routine that consent hardly holds any relevance in the way things are done. It feels trivial.” She speaks about how she navigates this “When I feel like someone is infringing on my personal space without my consent I stop them right there.” She also mentions in her talk about the wheelchair being part of what needs consent to be touched and manipulated by others. She speaks about her sister who gets things for her only when she asks for it, she says it means “that she respects my individuality and the norms we have agreed upon. My needs and wants are given importance to — I am not asked to do things I don’t want to do.”

Kavya’s articulation of consent suggests the care and respect for the other that consent actually takes and insinuates the many violations of consent possible in her everyday life.
How do you think the thoughts of gratitude and guilt that Srishti mentioned, the thoughts around shame and blame we spoke about might effect a person’s agency in asserting consent and boundaries and expressing violations?

How might the agency being taken away repeatedly affect their sense of self and contribute to further shame, blame and guilt?

What are some understandings about lives of persons with disabilities are standing out to you?

What does this get you thinking about how you might take this knowledge from the lived experiences of women with disabilities into your therapy rooms? What influence will it have on your conversations with women with disabilities on their sense of self, or on their mental health?
“I was hell bent on faking all happiness and confidence because I didn’t want anyone especially my parents to know what I was really going through — I was really hard on myself... I had a lot of rage and frustration. I didn’t know what to do with. The more people tried to put me in a box, the more I tried to push myself out of it.” — Parvathy Gopakumar, Pyaar Plus

Acting like ‘everything is ok’, like ‘I can do it’, like ‘everything is possible’ are some of the things that take a toll on people with disabilities as they have to do it over and over and against all the odds. Priyangee Guha and Rakshita Shekhar in their talk titled ‘Life on the spectrum’ in the Vellapanti series organized by Rising Flame talk about the toll on mental health masking takes for autistic people.

Many women on the autism spectrum discover they are autistic as adults, many self-diagnose and hence discover they have been masking all their lives, that their various experiences of ‘burnout’ or ‘depression’ came from the incessant masking that was required to be part of social situations in education, at work, in casual settings.

The reasons why persons with disabilities experience ‘anxiety’ or ‘depression’ is likely linked to ableism and needs to be examined and brought attention to.

**DISCRIMINATION**

In this talk titled ‘Say No to violence’, Sweta Mantri, writer and stand up comedian speaks of a particular incident of discrimination by a club — barring her entry into the club because of her disability and claiming it was not safe for her because it was dark inside. She speaks about her reassuring the person at the door that she is an adult and she would take care of herself and yet not being allowed into the club. This is one of many experiences of discrimination that persons with disabilities experience. There is a quote earlier of a woman telling us about being ‘exempted’ from work meetings because she was a wheel-chair user and the meeting location was not accessible; Rakshita Shekhar in the Vellapanti talk on ‘Life on the Spectrum’ referenced earlier speaks about being asked to leave her job when she told them she was autistic as she had not mentioned it during the interview and therefore had violated policy; and in another instance, she was told she was not ‘fit’ to work with autistic children being autistic herself.

✧ With your current understandings of ableism in our history and culture how might you respond to incidents like these in the therapeutic context?
What are things you want to hold on to from this manual?

What are things you want to do more research about or know more about?

ADDITIONAL REFERENCES:
Experiences of disability and effects of Ableism on people’s lives

RAKSHITA SHEKHAR — ‘I self-diagnosed my autism because no one else would’

WATCH THIS short film performance of the poem ‘Dear Hearing World’ by Raymond Antrobus

Closing Note

Deconstructing ableism is an ongoing process. We hope that this scaffolded some of the deconstruction and noticing of ableism and its effects. We hold on to the belief that deconstructing ableism helps us all. As mental health therapists, we hold on to the idea of ‘social change’ as a counter to ‘social control’ as Michael White, founder of narrative practices says.

We invite you to continue this journey with the self-learning manual, deconstructing ableism as you go along and supporting disabled people’s mental health that will build and nuance your understanding further.
The journey of creation of the self learning manual

The founder and Executive Director of Rising Flame Nidhi Goyal, as a disabled woman herself, has since few years been speaking about the invisibility of mental health experiences of persons across disabilities. She started this journey through her writings and talks around the issue. As a commitment to building and creating inclusive and sensitive support for persons with disabilities particularly in the times of COVID the manual was conceptualized by her.

This manual was then co-created through conversations between Nidhi Goyal, Srinidhi Raghavan, and Prathama Raghavan. Nidhi Goyal is founder and executive director of Rising Flame, Srinidhi Raghavan is co-lead, programmes of Rising Flame, Prathama Raghavan is a consultant of Rising Flame, and a developmental psychologist and mental health therapist.

This manual was created over a period of 8 months with Prathama Raghavan as the lead writer.

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Lastly, we are grateful to each and every disabled person who has spoken out, for sharing their experiences and stories with us and the world, so we could showcase them here to deconstruct ableism.