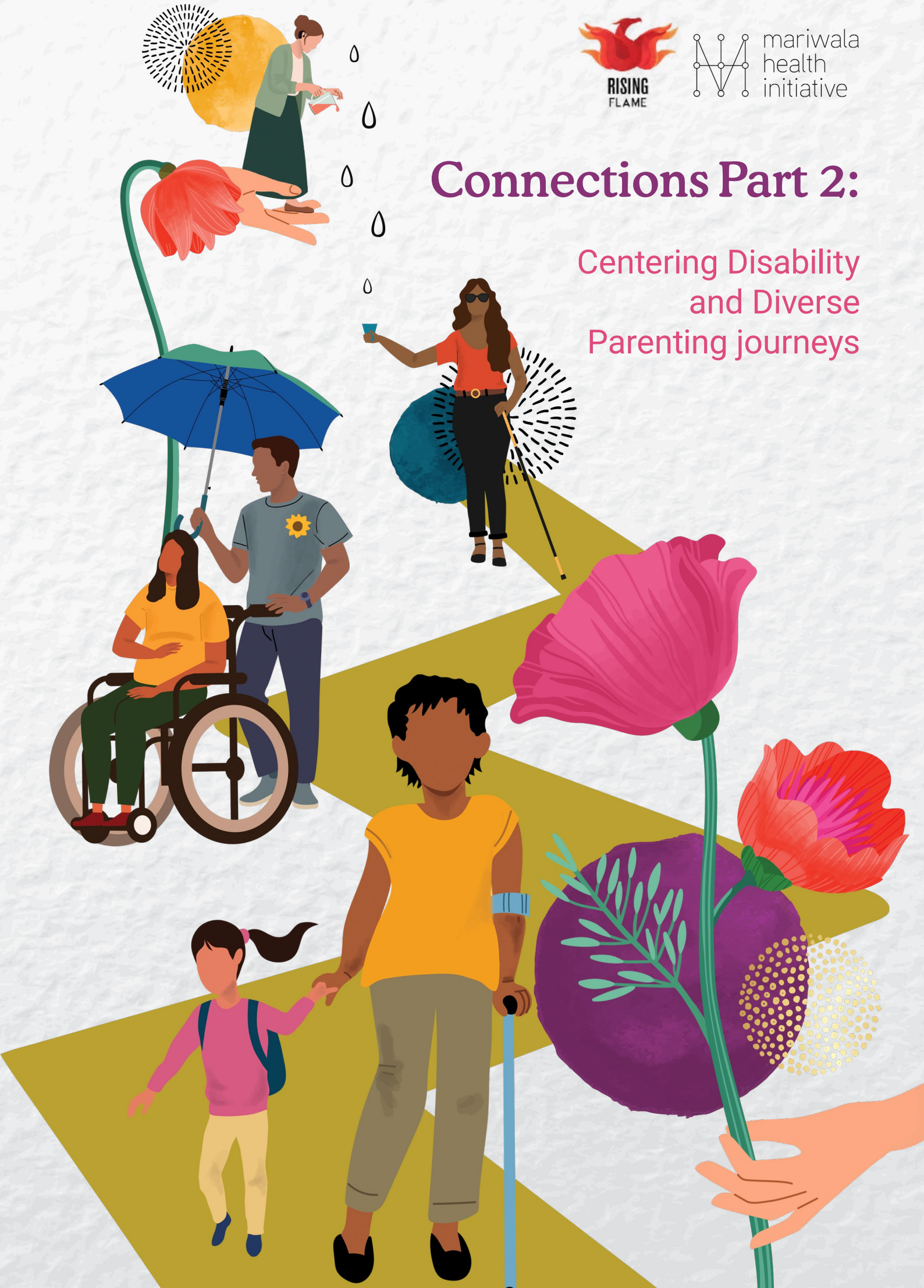
RISING FLAME

mariwala health initiative

Connections Part 2:

Centering Disability and Diverse Parenting journeys



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Rising Flame is a national award-winning, India-registered organisation working at the intersection of disability rights, gender justice, and youth leadership. In just eight years, Rising Flame has expanded its footprint across India and globally, advancing the recognition, protection, and promotion of the human rights of persons with disabilities with a specific focus on women and young people with disabilities.

Rising Flame envisions an inclusive and equitable world where diverse bodies, minds, and voices thrive with dignity; live free from discrimination, abuse, and violence; and enjoy equal access to opportunities, services, and decision-making spaces.

Founded in 2017 as an organisation led by women and persons with disabilities, Rising Flame is grounded in lived experience and community leadership. Our work centres persons with disabilities who stand at multiple intersections, enabling them to claim voice, create space, influence systems, and lead from the front. We work across areas of education and accessibility, leadership development and economic empowerment, mental health and sexual and reproductive health and rights, gender-based violence and access to justice and disability-inclusive policy and systems strengthening.

Brief Bios Of Our Team

The manual has been conceptualised, informed, authored, edited, and reviewed by experts who live with invisible and visible disabilities and have worked and lived closely with persons with disabilities. Dr Prathama Raghavan, an experienced mental health professional, is the lead author. Nidhi Goyal and Srinidhi Raghavan from Rising Flame have conceptualised, reviewed, and edited the manual.

Dr Prathama Raghavan (PhD):

Dr Prathama Raghavan has 20 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 well- being 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

Nidhi Goyal is the Founder and Executive Director of the National Award-winning non-profit Rising Flame. An activist, writer, researcher, trainer, artist, and India's first female disabled stand-up comedian, she has spent over 15 years challenging barriers and fostering social change. Her work has reached disabled and non-disabled communities across four continents and more than 35 countries. She has contributed to national and global policy processes and held leadership and advisory roles with organisations and institutions including UN Women global, AWID, National Human Rights Commission of India, FICCI, Dutch ministry and so on. Nidhi is widely recognised as a leading voice on disability rights, gender justice, accessibility, mental health, and inclusion, and has received multiple awards for her work and leadership.

Srinidhi Raghavan

Srinidhi Raghavan is a disabled feminist, educator, writer and researcher. She works at the intersections of gender, disability, sexuality and technology. She is Programmes Lead, Rising Flame. Her work for the past 15 years has focused on rights of persons with disabilities, on expanding our vocabulary around mental health, chronic illness and disability, on building more spaces where disabled people can thrive, on understanding how technology and disability intersect, on building social, emotional and disability support, and on imagining a feminist internet.

Author's Note

Every time I bring up disability in a class setting or in consultation with adults or families of children, I am confronted with the stereotypes that dominate disability. Saying the word itself is discomforting. I have come to believe that it is a resistance in itself to talk about disability in groups and families, to have it be said and not in hushed tones but in an acknowledgement of the marginalisation that it is. In naming ableism and recognising its effects we can together diminish its power over us. We can reclaim our agency in the face of it. Yes, it is systemic, it is pervasive but it draws power from the silence that surrounds it, the euphemisms that obscure it. In naming it we bring our attention to it, no longer going along with it, but subverting it in small and big ways. If this series of four manuals has been anything, it has been a documentation of the resistance and agency of disabled communities, the small and big revolutions that are a function of persons with disabilities simply navigating the world, growing, learning, working, loving, frolicking, writing, speaking, parenting as persons with disabilities. It has been an attempt to 'rename the problem' as persons with disabilities and thereby change how the problem is spoken about and allocate accountability where it should lie, not in the bodies and minds of persons with disabilities but within ableist discourses.

I am humbled by the conversations with persons with disabilities through this series both through direct interviews and through engaging with their writings and videos, through witnessing them in these myriad ways. My various privileges have allowed me to write these manuals. I feel an incredible responsibility and accountability to the content and to the voices of persons with disabilities who have been referenced through these manuals. I do not doubt that at another time, another person may have done something very different, that I myself may do something different in the future with the same themes. In this incredible responsibility I found the support and solidarity of Nidhi Goyal and Srinidhi Raghavan and all the people who have read, reviewed and given us their valuable feedback. This is by no means an individual work and it would have been impossible without the years of disability organising across the world, all the people who put themselves out there with so much vulnerability so that we may expand our understandings through their precious words and experiences. It would have not been possible without the social justice, feminist and anti-caste organising in India, people who against great odds continue to fight the systems that cause so much violence and destroy so many lives – disabled and non-disabled.

We hope that you will take these manuals and make them your own, use them in any spaces you encounter ableism which is every space. We hope you will find solidarity and resonance.

Introduction: Navigating Dominant Ideas about Parenting and Disability

We have spent the last three manuals deconstructing ableist ideas that influence lives of people with disabilities in various contexts. Many of those ideas of 'needing care and support versus being caregivers', 'dependence', also influence ideas of parenting. Questions like 'How is a person needing care going to be a parent?' 'How will they manage if the child hurts them self or is sick?' or 'How will you run behind the child?' are asked of them repeatedly. These are all questions we could legitimately ask anyone really. Parenting is a big job and most people take the decision as if it is just the next logical step and figure it out. People with disabilities also figure out school, college, university, going out, socialising, friendships, commuting, dating, sexuality like everyone else. They are doing this daily in their own lives, making their own unique choices and many times in the face of great inaccessibility and misgivings about their ability to do things. They are constantly navigating the sea of dominant ideas about what they can and cannot do and living life.

Let us deconstruct some of the dominant, ableist ideas that surround us regarding parenting with a disability. What are the ideas/ stories that are around us about a parent with a disability? As you consider this question, think about varied disabilities: visible, physical and locomotor disabilities, being blind or low vision, Deaf or hard of hearing, having a neurodevelopmental disability such as autism or a psychosocial disability such as bipolar or schizophrenia.

Questions for Reflection

- What stories / ideas are around us about parents with disabilities?
- How do these stories influence what society thinks about their parenting skills?
- How will these stories / ideas affect how we respond when a person with a disability expresses the desire to be a parent?

Interrogating ourselves with these questions and interrupting the automatic biases and ideas that may creep into our thoughts is important for better navigating these conversations in therapeutic contexts. These are also questions that may be important to explore with persons with disabilities themselves as they are thinking about being a parent to make more visible the dominant ideas around us and dismantle them. As persons with disabilities explore the choice of becoming a parent, these questions might support them in discerning the dominant ideas from their own preferred ways of thinking about parenting.

1. Choosing and Preparing to be a Parent

1.a. Considerations when Choosing and Preparing to be a Parent

"The entire perspective about how people think about somebody planning a family, when they are with disability is not that great. People feel that 'Why would you give birth to somebody with a disability?' But my question is, what if I choose to give birth to somebody average size, and tomorrow, that person, meets with an accident and then becomes disabled, or maybe he is born with a developmental or psychosocial disability. You know, anything and everything is pretty much a surprise. Nobody knows what's going to happen next. I come from a background where I have been a para badminton player. I know a lot of my friends who are wheelchair users or who are wearing a prosthetic leg because they met with an accident when they were 20-25 years old.... Disability cannot be judged like this. My entire summary is that being and even thinking about parenthood, is an individual choice. Being a mother is an individual choice. But as a society, people have a lot of questions and perspectives about it, and they don't completely agree with that fact."

- Disha, a person with dwarfism, parent of twins with dwarfism, as told during an interview with Rising Flame for this manual.

As Disha says simply, parenthood is a choice, one you make for yourself and with the people closest to you. It is as much an intimate choice as it is a public one, as once you embark on the journey of parenting you interact and encounter many people through the different systems that are part of the process of becoming a parent: family and friends, medical professionals and adoption authorities, education

professionals and community members to name a few. Hence the journey of parenting as a person with a disability leads you to encounter them all and their perceptions, supportive and not.

"I was born disabled with spina bifida (SB). Looking back to my first pregnancy in 2004, I didn't even identify as disabled, and my SB was something I tried to keep as hidden as possible. My own internalised ableism was huge, and the excitement of being pregnant was overshadowed with a sense of but... But what if the baby has SB like you? But what if the baby makes your SB worse? So, the relief that my first two pregnancies were indeed "healthy" was palpable. Well, like a eugenicist's worst nightmare, I eventually (third time lucky) did have a baby like me. A gorgeous, wonderful, beautiful baby with spina bifida. I remember the doctor telling us: "Your baby has SB. We don't know how serious it is. He might not be able to walk. Would you like a termination?"

A termination of my very, very wanted baby, purely because he was like me. Because a life like mine isn't worth living? What a load of bollocks.

I've never felt guilty for giving my baby SB, because I don't see my SB as a negative thing. Most of the time, it's neither positive nor negative, it's just a part of who I am. Still, I feel the judgment, I see the looks. Oh, the horror that I bred. How awfully irresponsible of me.

I think it's hard for society to view disabled people as being parents for so many reasons. First, we'd have to be having the sex to have the babies, and for some reason disabled people are all seen as pure and good and totally sexless."

- Nina Tame, 'I did not expect motherhood to legitimise me': Parenting with a disability', The Guardian.

Nina Tame in the above quote speaks about the internalised ableism and hiding her own disability (Spina Bifida) as much as possible. She speaks about the excitement of her first pregnancy being overshadowed by doubts about how she would manage her pregnancy, what if her child were to have spina bifida? What if pregnancy made her condition worse? She shares being relieved that in her first two pregnancies she had non-disabled babies. When her third baby had spina bifida, she explains that it was very clear to her that she would not terminate the pregnancy just because the child would have the same condition as her.

Questions for Reflection

- What does this confront you with about ideas that come to your mind? What about your answers to the questions above on ideas and stories around persons with disabilities and parenting? What does this quote get you thinking about your answers?

- What effects do you think having to hide a disability would have on asking for the practical and emotional support you need?

Nina Tame goes on to speak about how it is difficult for society to see disabled people as parents but also as sexual beings. One of the intentions of this self-learning manual on parenting is to support mental health workers having conversations with persons with disabilities to support them in making these decisions around the choice of parenting.

Biases about their own skills and capacities also affect disabled persons perception of themselves as prospective parents. What effects do you think it would have on their sense of themselves as parents or prospective parents?

Lived experiences (such as those through this manual) might support parents to reflect on their own thoughts and preferences. They also help us as mental health workers to challenge our own biases. One of the challenges in our societies with regards to stories and lived experiences is that majority and dominant experiences tend to be reflected in a lot of diversity, whereas experiences of minorities such as persons with disabilities and especially those communities at intersections of multiple marginalisations are often reduced to stereotypes and extrapolations based on limited representation.

In an interview with Rising Flame, Jamila, mother of a 10-year-old with Retinitis Pigmentosa (an eye disorder that leads to blindness, the same condition as hers and her partner's) speaks about consulting doctors about the possibility of their biological child also having this condition when they started thinking about having children.

"After 5 years (of marriage), we thought if we want to go through the pregnancy, we should talk to the doctor. Our concern was, we both have this 'eyesight issue' – will the baby also have it? We were referred to the genetic department – they told us that there will be 5% chance in the baby having the condition if it was a boy and none if it was a girl.

- Jamila, person with low vision with a child with low vision in an interview with Rising Flame for this manual.

(Jamila's quotes were translated from Hindi to English and she is quoted verbatim)

Jamila goes on to say that though it couldn't be confirmed right after birth, the family could see the signs that he had the condition. She says that given their background and how she and her partner were raised with support from their families, they also wanted to raise their son with 'the same exposure that any child should get'.

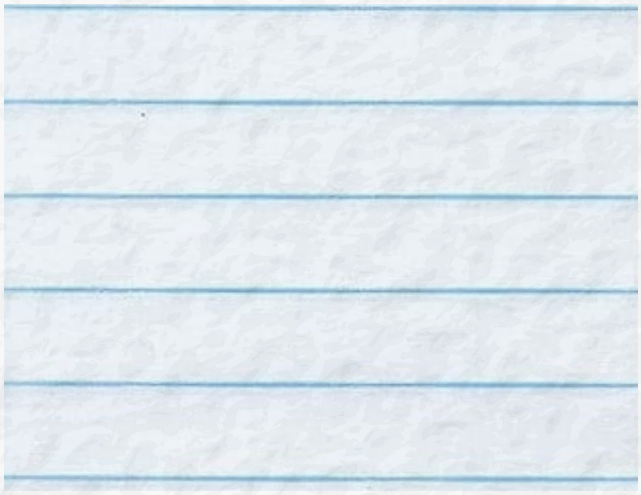
Like in the case of Nina above, considerations of abortion are often proposed when a foetus is likely to have the same condition as the parents. What information and support is provided to navigate these considerations and what factors play into the decisions of the parents is important to discern. As Disha says, while with some conditions it is possible to determine during pregnancy, with many conditions it is not. Then there is the possibility of an acquired disability during or after birth. How people navigate this depends a great deal on the kind of support the person receives from the medical professional, the family and close support system as well as their own life experiences of living with a disability, as Jamila mentions.

This is a decision that many individuals navigating pregnancy consider based on various circumstances and supports they

may or may not have access to. While some of them are personal support systems many of them may relate to systemic supports that disproportionately affect persons with disabilities and other marginalisations. Access barriers complicate many things for persons with disabilities, starting from the health system to the education system or physical infrastructure and support spaces. The considerations about passing on a condition that is genetic is very present for many parents with disabilities. Thinking about how we will navigate this conversation needs careful consideration and unpacking.

Questions for Reflection

- What systemic barriers contribute to these considerations in your opinion?
- What may be different in a world without access barriers and social biases about persons with disabilities?
- What are some barriers to accessing support that come to your mind in particular for persons with disabilities?
- What effects might these have on their choices of becoming parents?
- What effects could it have on their perception of themselves as prospective parents?



- These considerations about passing on conditions have to do with lack of access as much as they have to do with societal attitudes towards disability. How can we be rigorous in our therapeutic work to carefully bring attention to these societal attitudes and access barriers while affirming their choice to become parents?

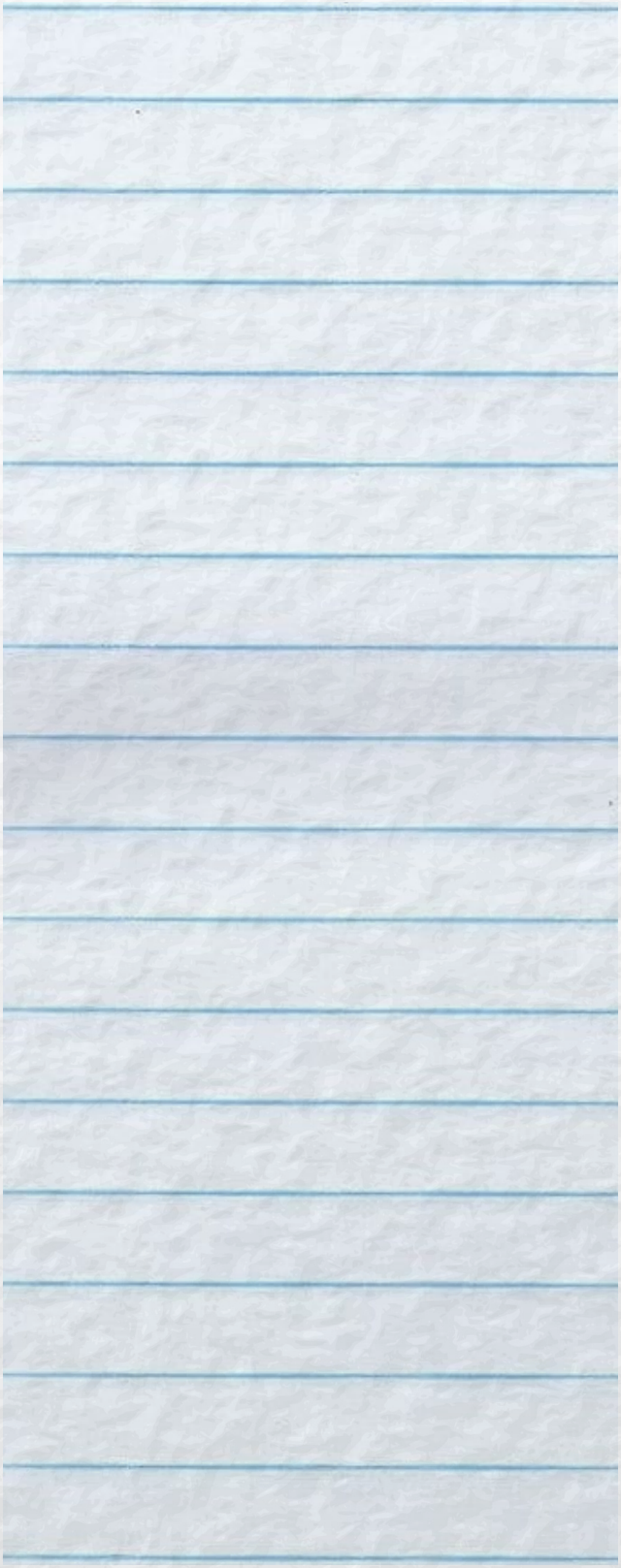
While we support parents with disabilities to navigate these dilemmas and challenges related to their parenting experience, it is also important to remember that they have agency in the choices they make and it is informed by values and know-hows that they already have. In our conversations as mental health workers, our intention is to make these skills, know-hows and values more visible to them. Making these skills and know-hows more visible may influence their choices in ways we cannot foresee. Our hope is that it facilitates the process of making choices and finding support while navigating an ableist world. In the last section of this manual, we offer some questions to support you to make these skills, know-hows and values more visible and support parents in holding on to them.

It seems important to discern that on one hand there are individual choices that each parent makes, on the other hand are systemic biases and barriers that do not favour certain choices and if these biases and barriers are not transformed, the agency in individual choices may be limited. While we support individuals in these journeys, we must also advocate for systemic biases and barriers to be transformed so that a child with a disability will have the same access as a non-disabled child.

As mental health professionals it is also important to participate in some kind of collective transformation and movement building work. All movements, any movement needs as

many people as possible to keep it going. What would be a small action you could take towards this?

Is there a community organisation you could become a part of or support some advocacy actions online?



1.b. Ways to Becoming a Parent

In an interview on the podcast Zen Mums Madhumita (a single mom with a disability) talks about her adoption journey as a single parent versus with a partner, as well as about the choice between adoption and becoming a biological parent. There are many important points she makes about understanding the adoption journey, finding resources and other adoptive parents, talking to family and friends – taking into consideration their concerns in making her decision. When speaking about adopting as a single parent with a disability, she says:

"As per the law and adoption process all people with disabilities can adopt. So there is nothing that is stopping you from adopting. At the same time like there is a rigorous process of checking everything, I think it is about whether the child is going to be okay, safe, whether the person is going to be able to raise the child and so on and so forth – that check irrespective of whether you are a person with a disability or not happens….

When you're going through the process like you are having to prove that financially you are equipped to support – you do need to say physically how are you going to support. There are questions in my case which did come up. 'You're looking at adopting a child between the age of 0-2years how are you going to lift the child and so on.' I did find my answers in that one I have my mother and she is going to support and I am going to have a nanny and a support system. You do need to practically prove what you are going to do….

Like with everything else a person with a disability finds their way of creatively doing it. You sort of figure that out."

- Madhumita, A different path to parenthood, Zen Mums podcast.

What stands out to you about her process and the steps she took?

The careful considerations she makes in preparing herself and having these conversations with her parents and finding them resources that would help them to understand are important to note. She says at one point in the interview, "Through the journey what is important to ask yourself is, who are the people who are readily bought in to it? There are going to be people who are not readily bought into it. So, how are you going to manage that? The way I have to learnt to manage is to learn where to ask, where to discuss and where to tell".

Discerning who to tell what, about decisions about becoming a parent seems important from this conversation. Supporting people to figure that out could be part of our role as mental health workers.

Jeeja Ghosh, a mother with cerebral palsy (CP) speaks about her adoption experience:

"Around 2016, my husband and I decided to adopt a child. So according to the process, we applied to CARA and then the legal process started. All the process was completed and then we had to wait for around one and a half years before we got to know there is a child for us and then you have to go and see her. So then my husband and I went to Orissa. It was a remote area, remote part

of Orissa. And when we went to the adoption centre, they told me how can you adopt a child. You have a psycho social disability you might turn violent and that would harm the child. I have Cerebral Palsy. I have no other issues. and why should I turn violent. They said, 'no, no, you can't adopt the child. Moreover how will you communicate with the child. You can't communicate so we can't give you the child. So we had to come back. After that we wrote to CARA and I contacted lawyers and disability rights activists who stood by me. And finally, we could reach the authorities in CARA in Delhi who were actually very supportive. Then they ordered the adoption agency, that no, you have to give them the child. So, this was the attitudinal barrier I faced, while adopting my child. Even now, as a disabled mother, I get vibes from the society that I am not a competent enough mother. Because of the disability that question of competency always comes in motherhood. Being a mother is a challenge whether you have a disability or you are so called "normal" but because of the disability the question of competency is always highlighted. This becomes the main focal point."

- *Jeeja Ghosh, Still We Rise, Rising Flame*.

In this ABC podcast, We've Got This: Fighting to Parent Eliza Hull (a mother who has a neurological condition) talks to parents with disabilities about their journey. Carol Taylor became quadriplegic after a car accident and was told she could never become pregnant. She speaks about her and her husband's journey with IVF and pregnancy.

"I just would not give up… and thank God my husband supported me. We had 8 years of IVF. So it was injections – Rob (her husband) would inject me every night so I could get to a point where I could produce eggs and then I'd go to the hospital and they would harvest the

eggs and I would go back to the hospital sometime later where we had a total of 15 embryos. We had a substantial amount of transfers and some of them took and I was pregnant and I lost my babies at 10-11 weeks.

...

For Robert and I we had a sense of humour and a lot of love and support.

...

So it was very emotional and very very hard to get that far and be told that yes, you're pregnant and then within that 1st trimester to lose them despite the fact that you would do everything in your power not to. After we went through those 15 embryos and all those miscarriages... Little did I know that a few months later I would fall pregnant naturally after all that time... I think we both just cried that was the first time that we'd ever achieved pregnancy without the assistance of so many doctors. I was terrified. I was worried that my baby was going to be born with huge anxieties because I was so frightened every single time we had to go for a scan.

... It is still overwhelming. I had to spend 5 months in bed to carry Darcy to 37 weeks...

And every day of being his mum is the greatest job in the world."

- Carol Taylor, We've Got This: fighting to parent, Life Matters, ABC.

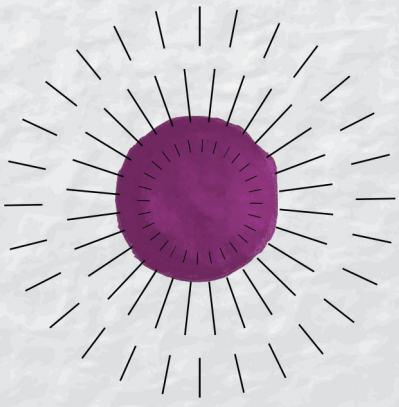
Questions for Reflection

- As you read the above experiences of adoption and IVF, what is standing out to you about the particularities for persons with disabilities?
- What are some things they have to navigate that they wouldn't have to if they were non-disabled?
- What values and principles are visible to you in these experiences?
- What does it get you thinking about dominant ideas about parenting with a disability?

- How might it relate to experiences of persons from other marginalisations such as caste, queerness, indigenous, other minority groups, etc.?

- How might you bring these understandings to your practice with persons with disabilities as well as those from other intersections of marginalisations?

  Knowing all our choices to become a parent can help us with openly exploring the desire of becoming a parent. This is true for anyone. The different ways/paths that disabled folks take to become parents, in itself is defying the system and people's expectations of them as many of the quotes in this manual assert. Knowing other stories of disabled folks can help to find resonance, feel seen, discover skills and know-hows and thus uncover agency. In many ways choosing to be a parent is a choice that challenges all these dominant ideas, but sometimes the choice results in taking difficult and lonely paths for a long while. These conversations could support persons with disabilities considering parenting to feel supported in their desire, to find their own particular ways of being and doing parenting and to find support in their close circles.



1.c. Finding Support in Becoming a Parent

Support systems are a wide spectrum that include personal, informal support systems such as family and friends as well as formal, professional support system that are usually paid services. People creatively find many support systems that are in between the two. In this section, we examine support systems from lived experiences of parents (prospective parents) with disabilities to understand their experiences and widen our perspectives. Here we explore some quotes from Disha and Amba.

Conversations with Partners, Family and Friends

"So when we got married, that marriage itself was a big deal for people… then later, what happened when we thought of having a family? … I get along with kids really well, and I like kids, so I obviously wanted one. And I spoke to him, and I asked him that, you know, what, if someday we plan for our kids, and give birth to somebody who's exactly like me. What do you feel for

that? So he said that, if I've got married to you and I've accepted you as a person, I don't think there is any challenge that I will have as a person. … But then I said, you know, it's not very easy, because people with dwarfism face a lot of red flags. And I said, you also being vertically short, you might have had those. So he said, We'll deal with it. If you are okay, I am okay. I asked that question, because for me, I come from a dwarfism family, and if I give birth to a dwarf, what if his parents or his family are not okay with that. So that was the bigger challenge for me. But then I think everybody in the family was very supportive. He was very supportive."

- Disha, person with dwarfism, parent of twins with dwarfism, in an interview with Rising Flame for this manual.

Amba Gauri in 'What to expect when you're expecting (and happen to live with mental health issues) for Skin Stories, Point of View talks about her journey of pregnancy and birth and navigating conversations with friends and medical professionals.

She starts the article with:

"I never quite understood what my friends thought about my mental health issues until I got pregnant. While they knew that I was an activist around disability and mental health with 'lived experience', most of them pussyfooted around it, maintaining poker faces when I would mention issues that I faced from time to time. When I told some of them, face to face, about my pregnancy, I noticed a split second where genuine concern crept onto their faces before they would reflect my smile with their own. There would be routine questions about morning sickness and maternity clothes, but also the, 'So, how are you doing?' It was kind of annoying."

Madhumita on the Zen Mums podcast referenced above explains that she spoke to her parents about the adoption process, took them for counselling and they met with single adoptive parents together. The support of her cousins and friends (chosen family as she calls it) also

affirmed her decision. Disha, Amba and Madhumita talk about their different experiences and how it felt to them. The parenting journey is one with huge uncertainties and responsibilities and anyone embarking on it needs support. However when ideas of families fit within the mainstream idea – the support is readily available and accessible. Parenting is encouraged and supported. For persons with disabilities the experiences are more diverse and support needs to be more intentional.

Questions for Reflection

- What does it get you thinking about nurturing support systems as parents with disabilities?
- What ableist ideas are they navigating and what skills are they using in navigating these?
- How might we support parents with disabilities to nurture support systems for themselves? What might be our role in that?

Navigating External Support Systems while Preparing to be a Parent

Amba Gauri in 'What to expect when you're expecting (and happen to live with mental health issues)' for Skin Stories by Point of View also talks about the different encounters with the medical community and the challenges she encountered. She recounts an experience at the Emergency Unit of a hospital:

"I'm already registered here,' I said, and my partner began to fish around my wallet among the dozens of hospital registration cards I had accumulated over the years.

'You are? Who is your gynaecologist?'

'I don't see a gynaecologist here. I'm here because this seemed to be an emergency.'

'Who is your doctor here? Let me call him.'

I then had to explain to her that I had registered here four years ago to see their rather famous psychiatrist, exactly twice. It didn't go well.

Her eyes widened. 'Are you on psychotic medication?' she asked.

'What, no! I mean, there's nothing wrong with being on…'

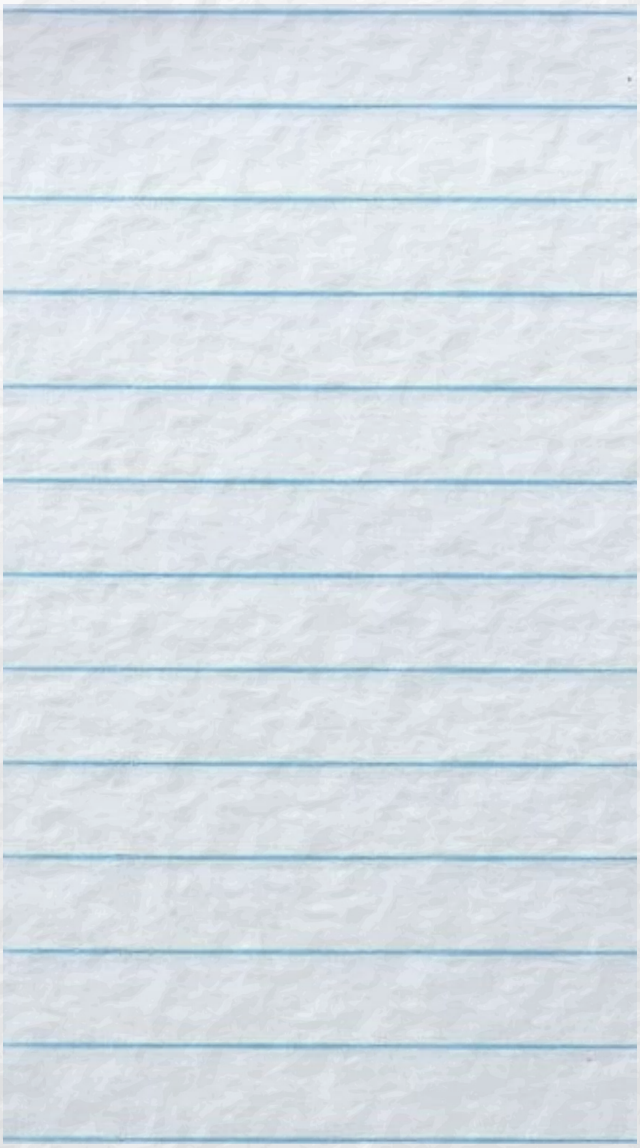
She pushed her face into mine. 'Are you sure you are pregnant?'

I realised from her expression that she honestly believed that I was in some kind of delusional state of phantom pregnancy. By then, my partner had fished out the folic acid prescription from the previous doctor. She looked at it, and seemed slightly convinced. I was ready to scream, but realised that I would play into a mental health stereotype if I did."

- Amba Gauri, 'What to expect when you're expecting (and happen to live with mental health issues)', Skin Stories, Point of View.

Questions for Reflection

- Amba's experiences bring attention to some dominant ideas about persons living with mental health conditions.
- What are some of those? What is implied about her becoming a parent in her interactions with the medical professional above?
- How might these ideas come in the way of people living with mental health conditions becoming parents or thinking of wanting to be parents or reaching out for support as parents living with mental health conditions?



Amba also writes about the support she received which she acknowledges having to do with her privileges:

"I went to see my psychiatrist, who had just about gotten back from her own maternity leave. I sat down in the chair and said, 'So, I'm pregnant.'
Her face broke out into the widest possible smile. 'Oh my God Amba,' she said, 'This is amazing news!' I was still recovering from her enthusiasm when she said, without missing a beat, 'You're going to be a fantastic mother.
....

I couldn't ask for a vote of confidence from anyone else, honestly. She promised to help me out with my mental health concerns and also pregnancy and motherhood life hacks she had developed over the last year.

Eventually, my various privileges and accumulated social capital ensured a

rather inclusive and positive experience."

- Amba Gauri, 'What to expect when you're expecting (and happen to live with mental health issues)', Skin Stories, Point of View.

This supportive voice Amba describes may not always be accessible for all expectant mothers with disabilities.

Disha describes her first prenatal consultation and sonography experience in her interview with Rising Flame for this manual:

"I was very sure if, if I could not give birth to a child at 35, 36 I would rather adopt. (We decided) Let's try for our own kids first. So we planned naturally, and I conceived naturally. I got to know that I was pregnant with twins in my first sonography.... The doctor told me that, Disha, there are likely chances that you might give birth to somebody like you. So I said, I would want to give birth to somebody like me. I'm pretty sure about it. So she's like, why would you want to have somebody with a genetic condition when you face so many consequences in life. So I said, there are no consequences that I face. There is a perspective of people in society which is not appropriate for me, but that has not bothered me beyond a point. So she said, it's because you are mentally strong. What if your kids go through something similar? Why would you want to do that mistake? And do you really want to think about this pregnancy again? I said, I have already thought about it, and my thought is that I will change my doctor. No, you are very negative, and I cannot come back to you, I'm very sure, she was shocked. And I actually changed my doctor. I went to a new doctor."

- Disha, person with dwarfism, parent of twins with dwarfism in an interview with Rising Flame.

Disha also subsequently found a supportive doctor who she consulted through her prenatal and postnatal care. She searched and found the supportive voice that she needed in a doctor who had also delivered her as a baby.

Questions for Reflection

- Are there similar ideas about persons with other disabilities? What are some of them that come to your mind?
- What effects do you think these experiences of Amba and Disha might have on their sense as parents?

Disha and Amba are articulate about their experiences, they have written about it and are advocates. When people have less access to supportive community and spaces of advocacy, the discourses are more likely to creep in. Thinking about these ideas is to make ourselves aware of them so they do not interfere in our therapeutic conversations. Making the discourses visible in their details helps us to identify them when they creep in. And perhaps learn to challenge these when they come up in conversation with others. Discourses are particular and context specific and therefore need to be identified with every person in every conversation. While we think here about some that have shown up in these quotes and experiences, there will surely be others. Thinking through what others may be present is essential in conversations with persons with disabilities.

2. Being a Parent as a Person with a Disability

We have been reading and thinking about the choice of becoming a parent and the diversity of experiences there. The skills that people use and the principles that they stand by. What about when they become parents and are navigating child – care, school, work and additional support? How do they navigate these? To put it simply like Madhumita says, 'Like with everything else, a person with disability finds their way of creatively doing it. You sort of figure it out.'

Here is an experience from James Catchpole as a disabled father from The Guardian article titled 'I did not expect motherhood to legitimise me': Parenting with a disability'

"I'm an amputee – missing all of one leg – and have been for as long as I can remember. I get around on crutches. For me as an amputee man, I've always found public perception to be ostensibly positive. You're thought of as heroic – superheroic, even. As a kid, you're "amazing", "a trooper". In your 20s, people start assuming you were a soldier and that you gave your limb for king and country. Then if you walk fast, climb stairs easily or do any kind of sport, you're "inspirational". So that was my life as Amputee Man. But then I morphed into Amputee Dad… As you might imagine, having a baby just added a new dimension. There's already a brilliantly unearned halo effect in being a dad out and about with a young baby. You're clearly doing better than just "helping out" and that's enough to buy you some very indulgent looks. The bar is low, let's face it. Being a capable father of a new-born on one leg and crutches clears that bar with some room to spare."

- James Catchpole, 'I did not expect motherhood to legitimise me': Parenting with a disability', The Guardian.

In the same article Lucy Catchpole James's partner who is a wheelchair user says:

"I did not expect motherhood to legitimise me. And yet it has. I think motherhood, or at least my motherhood – as the wheelchair-using mother of non-disabled children – acts to cancel out a lot of the things about me that the world found so disquieting. There are so many ways disabled people are infantilised – we're frequently just not seen as adults. But now, whereas before I had been infantilised, my children seem to act as an automatic pass to adulthood. Where I expected motherhood to open me up to even more judgment, it has had the opposite effect."

- Lucy Catchpole, 'I did not expect motherhood to legitimise me': Parenting with a disability', The Guardian.

In James and especially Lucy's experience, parenting became an 'automatic pass to adulthood' she says. She speaks about the infantalisation of persons with disabilities. Might this be the reason that people so often question if persons with disabilities can be parents? If people need any kind of access/accommodations, they are not 'independent' in the dominant sense of the world and can't therefore be parents?

2.a. Navigating Parenting and Childcare

Madhumita speaks poignantly about her own limitations and how she manages it. She gives the example of her son climbing up a tree and she is unable to help him down, or as he got bigger, she couldn't pick him up.

"There are some things I cannot do – the way I have learnt to deal with it is I know my limitations… I will get the nanny to support. This is the physical part of it. The emotional part of it because you want to hold the child sometimes…. how do you make peace with that – the fact that you are not doing that and that its somebody else. I have learnt to tell myself that there are many other things I am bringing into his life. All of us as parents have some limitations and mine is this."

In my conversation with Jamila, she describes all steps they took to support their child. In the initial stages

they got support from the immediate family, her parents and parents-in-law especially, in order to figure out and learn to care for their new born baby as all new parents have to do. She explains the challenge of beginning to give him alternate food other than breast milk. She says that she found it difficult to feed him liquid food and she needed help with that. But slowly learnt to take care of him on her own. She would make soft, semi-solid food and she would feed him this which was easier for her than liquid food. When the baby was 10 months, Jamila and her husband decided to move out of their in-laws home and live by themselves. They continued to have support from the family and later on they found further support from organisations and extended family as and when they needed it.

As I listened to Madhumita and Jamila, I began to wonder if non-disabled parents think so much about their limitations and the things they are not able to do with their children? We know that working mothers often feel like they are not doing enough for their children or are not present enough. This is once again a result of systemic biases that permit working fathers to not take part in child – care much but mothers' experience a sense of inadequacy if they are not able to work and care for the child in the same way they would if they had more time.

Sandhya on a Rising Flame panel on parenting with a disability at International Purple Fest 2024 speaks about navigating parenting and child-care responsibilities.

She says:

"You're paying the fees late because I've forgotten the date. And then that gets into an embarrassing situation. Because you get a call from school, sometimes the teacher reminds my child, and that's painful for my child, right? Or they asked me to get a printout for that assignment. And I have forgotten and I'm disorganised. And I'm all over the place. … So in terms of being just there for that child as a dependable person. And these are acts of care for your children, right? They grow up believing, yes, my mother has my back. And I know it sounds dismal. There are many, many things that I do with them that make me an okay parent. But these are the things, these are my challenges."

- Sandhya Menon, Disabled Parenting, Purple People, Rising Flame, International Purple Fest 2024.

Questions for Reflection

- Both Madhumita and Sandhya elude to the different things they do with their children and mention their limitations. What supports could be provided as a community to help parents navigate these responsibilities?

- If we imagined interdependence and co-existing beyond nuclear families, what kind of support could we imagine for these situations? For disabled parents, for single working parents, for parents from other marginalisations, for working class parents?

In the panel on parenting by Rising Flame titled 'Is it any different: A conversation on being a disabled mother' the panellists also recount the parenting strategies they used, the support they had or didn't have on their parenting journeys. They go on to talk about how decision making is taken away from disabled people and if you can't take decisions for yourself, you certainly can't take decisions for someone who depends on you.

Anandhi responding to a question about negotiating these perceptions with the other parent and partner says:

"It does hurt, I won't hide it. People go in that general perception that your husband must be looking after both of you or how does your husband manage working, looking after you and house work?"

She says she and her husband 'have made the whole thing into a kind of humour':

"It's going to take people time to change and you don't want to get hurt, so it becomes an internal joke. Yeah he said what everyone says!"

- Anandhi, Is it any different?, Rising Flame.

They go on to talk about the hurt they feel when the contributions they make are dismissed.

Jeeja also says:

"Any decision about the child used to be difficult. Of course my husband and I used to take the decisions together but some of his family had a very negative and hostile attitude."

Speaking about caregiving support and bonding with her child Jeeja says:

"I always have a caregiver to look after my child... as far as bonding with my child goes, we have good bonding. She always has understood that

Mama has some difficulties… One amazing thing I have found with my daughter is she understands every word I say since the very beginning."

- Jeeja Ghosh, Is it any different?, Rising Flame.

Jeeja's speech is impacted by CP, she emphasises here that her daughter understands her just fine. There are ways of being that are born out of the unique relationship of any parent and child and here it is similar, Jeeja's child understands her as she has always listened to her mother's way of speaking. These are some things that the ableist discourse might obscure. According to the discourses, all parental relationships follow the same framework and therefore systems have difficulty imagining the diversity of ways in which persons with disabilities navigate their parenting journeys.

Anandhi says at one point in the interview talking about her daughter:

"She will still seek me out if she wants something, she will come to me and say I want this or if she wants permission to do something saying 'Mama can I go there?' That's enough for me. What other people say doesn't validate me, what happens between us (as mother and daughter) validates me."

- Anandhi, Is it any different?, Rising Flame .

Questions for Reflection

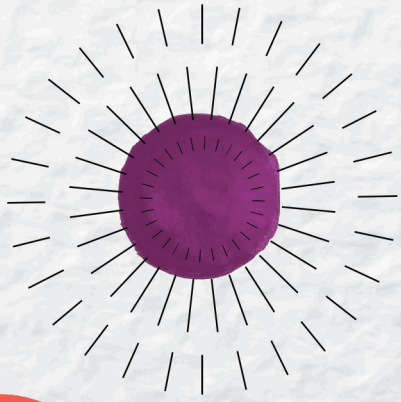
- What alternate stories about parenting stood out to you as you listened to Jeeja and Anandhi in this video and read the experiences above from Madhumita, Jamila and Sandhya?
- What skills and know-hows do they talk about in their parenting journeys?
- What has shifted in your own understanding of parenting as a person with a disability from these explorations?
- What are some ways you may want to hold onto these shifts in understanding?
- What might these shifts make possible for your therapeutic conversations with disabled and non-disabled people?
- What might this conversation make possible for a parent with a disability or for a person with a disability who is wanting to be a parent?

Witnessing the diversity of ways persons with disabilities navigate parenting journeys makes more space for all kinds of parenting. Knowing that someone else did it in this way and is speaking about it is a powerful catalyst to finding our own agency.

When there is representation of a diversity of ways of being, it could make space for more and more possibility and imagination.

2.b. Finding Support and a Support System

The phrase “it takes a village to raise a child” comes from an African proverb implying that it takes the support of many people to raise a child. This phrase is used in many contexts and is understood easily. Yet, persons with disabilities are often questioned about their ‘ability’ to parent and care for their children ‘independently’ though we know that all parents need the support of a ‘village’ to care for their children.



In this webinar organised by the National Research Centre for Parents with Disabilities, Brandeis University, USA parents with disabilities talk eloquently about their journeys becoming parents and the biases and challenges they had to navigate on that journey. They also speak about how they navigated these challenges and hurdles. Panellist Yomi Young speaks about one of her bigger challenges being unlearning the idea of independence and embracing the idea of interdependence as implied in the saying ‘it takes a village’. She goes on to say that as a disabled person who had the social services intrude in her life for most of childhood, she had worked hard to become ‘independent’ and not need their support. But as a parent she had to learn interdependence, build a community of support around her on her own terms, ask for help and nurture that community of support.

In this article on Skin Stories by Point of View, Srinidhi Raghavan talks to Nilofer and her husband Sharif a deaf couple who live in Sangli, Maharashtra about their parenting experience. Niloufer speaks about the support she needed as a deaf parent:

"When I lived with my mother right after delivery, she would sleep in the same room as me. She would nudge me awake when the baby woke up in the night crying. I would then respond to the baby’s needs."

Sharif's parents came to live with the couple temporarily when Niloufer moved back to living with Sharif.

"It was not discussed but they knew I needed help in looking after the baby. I could only respond to her needs if I never took my eyes off her. But since I also needed to cook and clean, this was impossible. Those months we would all sleep together in the living room. His mother would wake me up every time the baby cried or seemed upset."

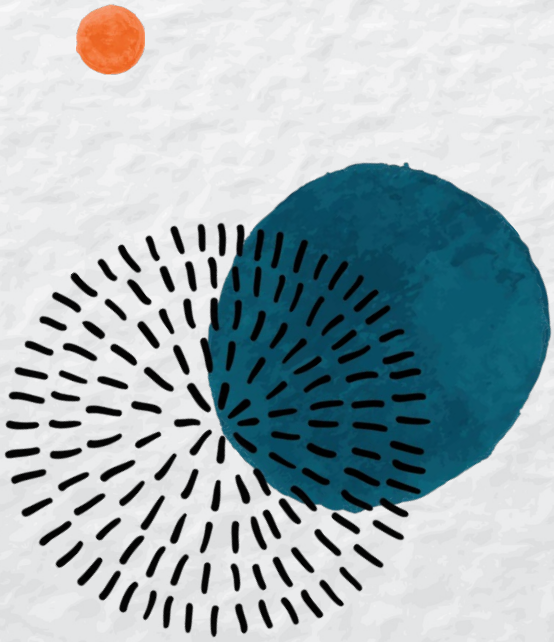
- Sharif and Niloufer, Hopes and fears: The parenting journey of a couple with disabilities in Sangli, by Srinidhi Raghavan, Skin Stories, Point of View.

As with Sharif and Niloufer, Prasad also shares on the parenting panel at Purple Fest about learning to adapt care strategies to their particular situation of being Deaf parents. He says:

"So our son used to sleep in between us when he was very young. So if he starts crying at night, so my wife would wake up, or I would wake up so that we are not disregarding him for hours. Because I will tell you that sometimes it happens, like we can't like keep our doors closed. So we have neighbours, also nearby. So if our son is crying, if my wife is in the kitchen or like just went for rest, and the kid was sleeping and the kid woke up, my wife would not get to know the kid is crying for us, may be the kid needs milk or food or any care. So the neighbour's help we took in the early years."

- Prasad Joshi, Disabled Parenting, Purple People, Rising Flame, International Purple Fest 2024.

Prasad goes on to speak about technologies that can now be used to support Deaf parents – like sounds detectors that signal with blinking lights so parents can understand that their child is awake.



In the interview on the podcast Zen Mums, Madhumita, a single parent with a disability speaks about her chosen family. She says as a single child her friends were her chosen family. She speaks about 'a different kind of acceptance she had as a person with a disability from these friends around her' (children of friends of her parents) that she grew up with, which gave her confidence and belief. These conversations remind us of the value of supportive people and the difference it makes to have this around you. Whether it is your family, friends, neighbours or a disability community having these voices of support allows people to imagine possibilities for themselves.

Questions for Reflection

- What effect are these testimonies having on your perceptions of parents with disabilities?
- What difference do you think it would make for parents with disabilities to have communities of support they could share their experiences with and learn from?
- What might become more possible for them if they could have access to these supports?

Interdependence is one of the core principles of the Disability Justice Framework along with intersectionality and centering the most marginalised. We explored this at length in Holding Space: Understanding Invisible disabilities and intersectionality. Disability Justice seeks to imagine and create communities of mutual care and support for persons with disabilities.

Communities where people with disabilities can live full lives, have the support they need and thrive in their own unique ways. The above examples are disability justice in action.

2.c. Navigating Biases and Societal Attitudes

In the panel on parenting by Rising Flame titled 'Is it any different: A conversation on being a disabled mother' when asked about the stigma she faced from people around her about being a parent Jeeja says:

"I will break it up into two parts -one is caregiving and one is attitudinal. I always have a caregiver to look after my child."

She goes on to talk about the attitudinal aspects and says:

"People didn't say it to my face but I was made to feel like an inadequate mother."

Another example she gives is:

"When somebody buys a gift for the child, it is given to the mother, this relative she does it even now, she will give it to the caregiver and tells her what to do, what not to do. I feel insulted, but to maintain the peace, I don't say much."

Sandhya on a Rising Flame panel on parenting with a disability at International Purple Fest 2024 speaks about the judgement she faces for some days not being able to get out of bed and get her children dressed and make them breakfast before school, etc. She also speaks about how both mental health conditions she experiences have the 'side-effect of a violent temper'. When asked how she responds to this, she says:

"This leads to me withdrawing or then just exploding and saying "mind your own business, I know what I am doing with my children" that is with my family.

Society wise I respond a little more kindly because they don't see me on a day-to-day basis and most of them come at me curiously but also to say listen should you have had children and should you be with them alone do you not worry that they might have terrible lives as adults? That's the kind of question that really sort of bothers me and to that my response is:

'I don't know how good a parent are you? You don't

have a mental illness at least not a diagnosed one but how good a parent are you? Can we compare notes?'

So for me I use that when it's outside my family, I use that as an opportunity to maybe learn something from them, maybe I don't know some parenting things, maybe I can learn from them. Or as an opportunity to open up and say "Hey, a lot of us deal with the same challenges in similar ways and I might deal with it in a slightly more intense way because of my mental illness."

- Sandhya Menon, Disabled Parenting, Purple People, Rising Flame, International Purple Fest 2024.

Prasad on the same panel shared:

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

- Prasad Joshi, Disabled Parenting, Purple People, Rising Flame, International Purple Fest 2024.

Questions for Reflection

- As mental health workers when we are part of support systems to persons with disabilities, what actions can we take that would support any person with a disability to find that supportive, encouraging community? What is our role in that? What steps could we take to make that possible?

- Other than individual support, what other kinds of support are also needed? How might we as mental health workers make this possible?

Reading Jeeja, Sandhya and Prasad's quotes gets us thinking about the subtle and not so subtle ways parents with disabilities are judged in their ways of parenting and how deeply hurtful it might be. There is of course the dealing with their emotions as they are on the receiving end of these perceptions but it is also about the effect it has on their sense of self. As Sandhya says above many parents deal with the same challenges in similar ways and yet when it is a person with a disability the judgement is more present. It is important to acknowledge the agency of the mother as a parent and not just as a person with disability and therefore receiver of care. Mothers as parents with disabilities take decisions and make choices and creatively find the

support that they need. What perhaps needs more consideration is how the systems that are questioning a disabled person's capacity to be a parent could create more support systems for parents with disabilities.

2.d. Speaking about Disability with your Child

As parents with disabilities, speaking about disability with your child seems inevitable. How do parents navigate that? What can we learn from them? What difference might it make for a child to be exposed to disability in this way? These are questions that are relevant and interesting to explore. While social norms think of disability as undesirable, there is something particularly unique about growing up with a close relationship to disability. We know from experience of working in disability that having a close relationship to disability is one of the main influences for having an open mind towards it. In this section we hear from parents who have spoken about their disabilities with their children in creative and practical ways. There is much to learn from them.

Here is a quote from Cathy Reay, a mother with achondroplasia (a form of dwarfism) from The Guardian article, I did not expect motherhood to legitimise me': parenting with a disability.

"As I grew up, I began to desire children who would create the kind of bustling, noisy home I had always craved. But I was conflicted by the ableism I faced, both in society and internally. I didn't think I would ever meet somebody who would want to have children with me. When I did eventually fall in love, our relationship blossomed sure and fast, as did our family. It was like I'd been holding my breath and I could suddenly exhale.

People with achondroplasia, which is the type of dwarfism I have, have children by caesarean section. My partner and I both worried about how I would recover, how I would manage the physical part of being a parent. These worries were never a reason to deter either of us, though.

My daughters knew early on that we are all disabled. I've always named our disability and we talk through the things they're concerned about. Non-disabled parents

don't know what to do with me, because I am defying all the things they think about disability. I am pushing up against misconceptions like: "Disabled people don't have sex" or "No one would ever be attracted to a disabled person" or that "Disabled people can't conceive" and "Disabled people can't look after other people, they can't have dependents".

My kids are marginalised in more ways than I am, and it's vital that I help them to understand how the world sees their disability, their race, their gender. Their identities aren't a problem – ableism, racism and sexism are. They're both very aware that they're disabled. People's attitudes are something I constantly have to navigate with them as a parent."

- Cathy Reay, I did not expect motherhood to legitimise me': parenting with a disability, The Guardian

Disha in the conversation with Rising Flame speaks about this conversation with her 3 year old twins. She says that she knows from her work with parents with children with dwarfism that they begin to understand they are different at ages 4-5. So though she doesn't mention the condition or name it with her children, she has conversations with them about diverse bodies.

"A few days back, my son told me, in Gujarati that Mama 'tu nani chen', which means that you are small. So my son kind of understands that we all are small. He's on and off pointed this to us that, you know, you are small. I am small. So I told him, 'Yes, we are a small family.' I know it's still another six months or a year when they will completely understand that they are different.

Every time we have these bedtime stories where I train them already, both my son and daughter, that there are few things good and bad about society. We should adopt good ones. I tell him stories where there was a fat elephant and there was

a thin giraffe. And you know, when they fought, the fat elephant was strong, but because giraffe was tall, he won. Sometimes I tell them that because giraffe was too tall, he could not cross the bridge, but the fat elephant could. So I tell them how fat and thin, how tall and short have their own, you know, good and bad, strengths and weaknesses. So I am training them about how every structure of a body type is different, yet very special."

- Disha, person with dwarfism, parent of twins with dwarfism in an interview with Rising Flame.

Like Disha, Jamila also has a child who has the same condition as his parents (Retinitis pigmentosa). She speaks about her son's questions around why he couldn't do certain things and being irritated in darkness or going to sleep. She says:

"My child would ask my husband (who is blind) to read something and he would say 'Beta, I can't see'. And the child would ask you can't see at all and my husband would say, yes, I can't see at all. He began to understand at 2 years. I started telling him then that he also had this condition, He couldn't understand everything but slowly he began to understand and started to accept his disability. At 5-6 years he began to understand his disability and he had understood our disability."

- Jamila, person with low vision with a child with low vision in an interview with Rising Flame.

Jamila speaks about how they would tell him that he should try to navigate in the darkness and not ask to be carried as he got older. She says:

'when children accept their condition when they are young it is easier for them.'

As we can see different parents have taken different approaches and have had to speak about different things depending on their condition. Sandhya Menon on the Purple Fest panel on parenting speaks about talking to her children about her mental health conditions. She speaks vulnerably about the effect of her suicide attempts on her children and talking to them about it.

"So when I speak in public, people often ask me, 'How do your children react to you? Do they think you are a weird mother?' And I say well, yes, they do. But they also know that I have a mental illness because we have an open conversation about it. It sounds a bit pompous, but I'm also a suicide survivor in terms of I attempted because of wherever, whatever mental illnesses... I have attempted suicide twice. And there came a point where I had to discuss this with my children because they came to know about it.

And so then, there is a situation where my children are unable to be their full selves, because they think, Oh, if amma gets distressed, what happens if she tries to kill herself? Right? So there is that constant fear that I don't think any child should live with."

- Sandhya Menon, Disabled Parenting, Purple People, Rising Flame, International Purple Fest 2024.

Questions for Reflection

- What does this get you thinking about why it might be important to have these conversations with children?
- What might be some ways as mental health workers we could support parents in these conversations?
- How can we support parents to not blame themselves but also find the support they need?

The stance that feels important is that parenting, all parenting takes support and community. If as a society we considered that parenting is a shared endeavour then what kind of supports will be provided for all parents with or without disabilities?

We have explored some difficult themes in this manual. Listening to lived experiences is the best way to learn and unlearn. Disabled people living their lives and raising kids in their own ways is making the way forward for disability justice in the world. Many of the people talking about their experiences here have come to become parents and continue parenting against great odds and prejudices in society. The intention of this manual like all the others is for mental health workers to become better equipped to have therapeutic conversations on all aspects of life with persons with disabilities. The idea that when we are in therapeutic relationships with persons with disabilities we do not solely talk about their disability, we talk about life, work, relationships, the future, parenting. In order to navigate these conversations it is important for us to widen our perspectives, check the social biases that have found their way into our ways of working. Disability is diversity, it is a part of life, it is a part of our world, it is a part of our history and it will be a part of our future.

3. Exercises for Therapeutic Conversations

In the following section we offer some sets of questions to start some conversations with persons with disabilities on parenting journeys to help them uncover and value their skills and wisdom, to help them highlight their own values and principles and take action and make choices from a place of agency. As we have learnt through these experiences, they are already doing it.

These exercises are ideas, explorations offered as openings to conversations around parenting with persons with disabilities. While they are offered with the intention of using in this context, they can be modified and adapted for use in other contexts as well. These exercises are informed by narrative practices (Michael White and David Epston) and politicised somatic practices (Staci Haines).

They can be used as standalone exercises, but also try integrating them into conversations you may be already having in your consultations.

3.a. Exploring Unique and Particular Skills and Values

The questions below offer some pathways to reflect on what might be preferred ways of parenting and care for parents with disabilities. These can also be important for mental health workers to think about for themselves as well as use as prompts for conversations with persons with disabilities in supporting them on their parenting journeys.

1. What do you think might be some unique and particular skills and ways of parenting that the dominant ableist ideas might obscure?

2. What might be some values and principles that you as disabled parent/s bring into your parenting that would be particular to your experience in the world?

3. What are some ways these values and principles are already visible in your life today?

4. What are some of your hopes from becoming a parent? What effects would it have on your personal life (family, friendships, intimate partner relationship)? What effects would it have on your professional life? What might be your opinion

about these effects? Is it ok with you? What do you think about it?

5. How might these hopes, values and principles you mentioned show up in the parenting actions you take and choices you make?

6. How would they be visible in the ways in which you may care for a child?

7. What difference would it make in your parenting journey?

3.b. Navigating Intergenerational Cycles of Trauma

In this exercise we have the intention of uncovering the ideas / tendencies that have come to us from around us, from our families and communities, media and society. We attempt to discern which of these we would like to hold on to and which of these we would like to let go of. It might be useful at the end of this exercise to do some kind of practice of letting go of those ideas we no longer want to hold onto.

1. Look at images, representations of parenting all around you, in ads, movies, media. What do you see? What does this tell you about how you should be? Let's write these down.

2. Let us now add to this what you see in your family and community around parenting. What does this tell you about how you should be? If you had turned out exactly like this, how would you be?

3. Let us now think about what you see in larger society around parenting. What does this add to what kind of parent you are supposed to be? If you turned out to be this way – what would matter to you? What would you care about?

4. You may also think about these same questions now from the perspective of being a person with a disability (not necessarily a parent).

5. Once you have listed down these 'should and musts' that we have inherited, we will look through each of them and decide how we feel about them. Do you care about this? is it important to you? If no, why is it not important? If it is then why do you hold this as important. This way you take a stance about each of these inherited 'shoulds and musts'

6. Once you have done that a list that fits with what you want, we can add to that list, with the help of these questions below:

7. What do you long for? What do you care about? If you had the permission, encouragement, support to do anything, what would you like for yourself?

8. Imagine you had a life that deeply aligned with your desires and

dreams – what would that look like?

9. What steps could you take that would take you even a little bit closer to these dreams and desires?

10. How can we do this together through conversation?

3.c. Nurturing Your Disability Identity

Let us start with a story about a particular experience in relationship to your disability. It can be an experience when you were a child, as a student, with friends or family. Think about an experience where you felt something or thought something or said something or did something that was in alignment with a value that has become important to you or you stood up against something that was not okay with you.

1. Tell me more about what was happening around you when you had this experience. Where were you? Who was with you? What do you remember about the place and time?

2. What sort of feeling, thought, action happened in this moment? How would you name it now? What were you trying to do in feeling/ thinking / taking this action? If you could name it as a skill or a know-how what would you call it?
3. How has this skill or know-how supported you at other times in navigating experiences or conversations around your disability? Tell me about another time when you used this skill/ know-how?

4. What does this skill or know-how tell you about what stance you take about disability? What does it say about what values and principles are important to you in the context of disability?

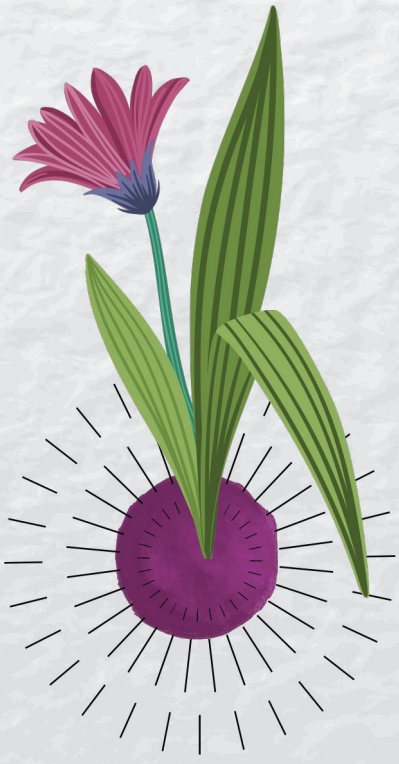
5. What would you want there to be more of in the world and what would you want there to be less of? What would make the world more supportive of persons with disabilities in general and you in particular?

6. What are some steps you yourself are taking towards this world? This could be in your personal life or your public life/ visible actions or invisible actions?

7. What are some steps you are taking or would like to take that stand with your values and principles around disability?

8. How would you like this to be witnessed by your child? What would you like them to see you doing with regards to your values around disability?

9. How might you talk to them about this intentionally? What have you already done? What more would you like to do?



3.d. Your Support and Solidarity Team

Adapted from Solidarity Team Exercises by Vikki Reynolds

This is an exercise to reflect on who could be part of your solidarity team. Members of your solidarity team stand by you, support you and offer you a space to reflect or think through any difficult dilemmas you may have. They can be people around you, people who have passed on, younger people, animals you have or have had a relationship with or nature beings.

1. Who could be part of your solidarity team? Think of 3-5 people / beings. It can even be people you appreciate but are not around you - like poets, writers, community leaders past or present. These are people who could keep you accountable and engaged in your work. What or who support you to keep doing what you are doing?

2. Is the name solidarity / support team ok or would you like to call this team by some other name? What name would you use?

3. How might you reach out to them? For what in particular might you reach out to them?

4. How might they support you? If it is people around you, you might actually reach out to them and ask for support, if it is animals - how might you get their support? If it is writers, poets, community leaders or elders who are no longer around you - you might imagine asking them for support and see what comes when you do that.
5. Keep your solidarity team close to you - reach out to them for support when you need it.

Closing note

Understanding the lived experiences of parents with disabilities offers us more than insight into disability and parenting. It invites us to question some of our deepest assumptions about care, dependence, autonomy, family and belonging. These stories move us away from the narrow and harmful idea of disability as a lack, a deficit or a burden. Instead, they illuminate the many ways in which people create, nurture and sustain relationships, families and communities with creativity, determination, vulnerability and love.

The journeys in this manual challenge dominant narratives of who gets to be a parent and what good parenting is supposed to look like. They show us that parenting is never an individual act. It is built through interdependence, support, adaptation, negotiation and care. Parents with disabilities make visible what has always been true: that all of us rely on one another, even if some forms of dependence are more socially accepted than others. In doing so, they expand our imagination of parenting itself.

These stories do not shy away from the realities of ableism, exclusion, self-doubt or exhaustion. Yet they also reveal joy, humour, wisdom, tenderness and resilience. They show people refusing limiting expectations, advocating for themselves and their children, building support systems where none existed, and reimagining what family and caregiving can be. Through both quiet acts of everyday living and bold acts of resistance, they challenge prejudice and create pathways for others to follow.

As we come to the end of this manual series, we return to a theme that has run through all four manuals: disability is not a tragedy to be overcome, but a way of being in the world that reveals both the violence of exclusion and the possibilities of connection. The stories gathered here remind us that disabled lives are not defined by what they lack, but by the richness of their relationships, their knowledge, their struggles, their pleasures and their dreams.

We hope these narratives support your own journey of learning and unlearning. We hope they encourage you to notice ableism where it operates, to question the stories you have inherited, and to imagine more expansive ways of living together. Most of all, we hope they leave you with a deeper appreciation for the many forms that care can take and for the countless ways people love, nurture and create belonging.

May these manuals continue to travel beyond these pages—into classrooms, homes, workplaces, communities and movements. May they spark conversations, solidarity and action. And may they remind us that a more just world becomes possible when we make space for all the ways of being human.

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