

# Discourses on Disability

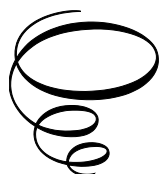


# Discourses on Disability

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Anju Sosan George

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Discourses on Disability

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To  
Cinny Rachel Mathew,  
with all the love a heart can hold



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# INTRODUCTION

ANJU SOSAN GEORGE

For Anu Kalikal, art is therapy. The tremors that come to her like waves that signal her schizophrenia and bipolar disorder do not limit her buoyant spirit. She runs vivid colours on her palette and, immersing herself in her work, she gives her mind and body time to respond to her seizures. The same resilience is there on the cover of this book, selected after hours of careful consideration. Through a brilliant conceptualisation of a stag in a striking melange of colours but with a shortened horn, Anu has been able to project the idea of disability from a positive angle. The spirit of the stag in the painting is unbroken; its gaze is proud. It is evident that the stag is not defined by its brokenness; rather, its striking rainbow of colours reflects a celebration of life.

The changing human engagement with disability has packed multiple meanings into understanding the word *disability*. Reading *ability* as competence and *disability* as the “other” of *ability* is a misinterpretation. The word *disability* masquerades as non-identity.<sup>1</sup> Specific or abstract meanings of the word *disability* cannot be located away from the word *ability*. The shades of meaning of this word stand fudged when used in everyday discourse. Because of their linguistic situatedness, it is difficult for terms like *disabled* to move away from the burden of othering. However, the life writings of persons with disabilities (PWD) are a reminder that these challenges are all the more forceful and vivid in a posthuman world.

If language possesses us, the word *disability* affirms the lack of *ability*. The prefix *dis-* evolved from the Latin origin, which implies a negative. It indicates the “lack of” or “opposite of” or “apart, away” from the word to which it is affixed (e.g., *disobey*, *dishonest*, or *displease*). When attached to the root word *ability*, *dis-* negates the “state or condition of being able; capacity to do or act.”<sup>2</sup> This linguistic framework of loss, though

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<sup>1</sup> Tobin Siebers, *Disability Theory* (Ann Arbor: University of Michigan Press, 2008).

<sup>2</sup> Online Etymology Dictionary, s. v. “disability,” accessed 10 May 2021,

inadvertently subliminal, extends to the political understanding of the term. In the ableist dictum, in the binary abled-disabled, it is near impossible to free ourselves of the negative affective categories the term has accrued over the years. The cultural structuring of the word *disability*, in the plainest sense, connotes dependency, impairment, handicap, or barriers. It has emerged to signify not merely a bodily impairment but restrictive social environments that affect an individual's productivity. Lennard Davis in his "dismodernist approach to identity politics,"<sup>3</sup> Rosemarie Garland Thomson in her arguments on the "normate,"<sup>4</sup> and Robert McRuer in "cripistemologies"<sup>5</sup> are some who have attempted to break away from this construction of language.

Discussions on disability are complex and diverse due to the sociocultural nexus they emerge from and the diverse assemblages of power they answer to. The discipline is rooted in half a century of both political activism and subsequent academic exchanges<sup>6</sup> that emerged in the global West. Civil rights movements that were brewed in the political angst of the late twentieth century gave way to discussions on the rights of the disabled along with others fighting marginalisation.<sup>7</sup> The paradigm shift in the discipline came while addressing disability solely from a medical perspective (medical model) to recognising disability as a construct of social exclusion (social model).<sup>8</sup> The need to address the stigma of intellectual disabilities and end institutional abuses, counter eugenics, the call for independent living, human rights, and bioethics frame policy responses over the years in the global West. Contemporary discussions reposition disability as a

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<https://www.etymonline.com/word/disability#:~:text=late%2014c.%2C%20%22state%20or,%2D17c.>

<sup>3</sup> Lennard J. Davis, "The End of Identity Politics and the Beginning of Dismodernism," in *The Disability Studies Reader*, ed. Lennard J. Davis (New York: Routledge, 2006), 231–42.

<sup>4</sup> Rosemarie Garland Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture* (New York: Columbia, 1996).

<sup>5</sup> Robert McRuer, *Crip Theory: Cultural Signs of Queerness and Disability* (New York: New York University Press, 2006).

<sup>6</sup> Lennard J. Davis, *The Disability Studies Reader* (New York: Routledge, 2013); Tom Shakespeare, *Disability Rights and Wrongs Revisited* (New York: Routledge, 2014); Shaun Grech and Karen Soldatic, eds., *Disability in the Global South: The Critical Handbook* (New York: Springer International, 2016).

<sup>7</sup> Dan Goodley and Katherine Runswick-Cole, "The Violence of Disablism," *Sociology of Health and Illness* 33, no. 4 (2011): 602–17, <https://doi.org/10.1111/j.1467-9566.2010.01302.>

<sup>8</sup> Colin Barnes, "Re-thinking Disability, Work and Welfare," *Sociology Compass* 6, no. 6 (2012): 472–84, <https://doi.org/10.1111/j.1751-9020.2012.00464.x>.

problem of social justice.<sup>9</sup> What was once considered impossible and radical have become policy changes, acceptable in its cultural reiteration.

Disability studies is an academic discipline that enfolds both theoretical and activist rubrics. It explores how variations of the body-mind, whether physical, cognitive, sensory, or behavioural, categorised as disabilities are socio-political, cultural, economic, or linguistic constructed notions. Each variation of the body-mind generates meanings across cultures and undergoes political signification. How we prod, expose, and understand this construction of the identity of the “disabled” underlines disability studies as a discipline.

Recent responses to disability investigate how the disabled person is subject to modalities of power. Marta Russell<sup>10</sup> explores the changing position within the system of capitalist production, Mitchell and Snyder<sup>11</sup> question discriminatory social barriers in the age of neoliberalism. Conceptual ideas on disability as identity and well-being in Kristiansen<sup>12</sup> or Ralston and Ho<sup>13</sup> place disability in a phenomenological position. Critique of the overarching metanarratives of disability<sup>14</sup> questions the normative social order. Theological intersections<sup>15</sup> and socio-political, ethical debates in the narrow divide between dependency and autonomy are traced in the works of Clifton<sup>16</sup> and Cohen et al.<sup>17</sup> Disability aesthetics, the theorisation of disability in modern art, and its refusal to recognise able-bodiedness as a

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<sup>9</sup> Nick Watson and Simo Vehmas, *Routledge Handbook of Disability Studies* (New York: Routledge, 2020).

<sup>10</sup> Marta Russell, *Capitalism and Disability: Selected Writings by Marta Russell*, ed. Keith Rosenthal (Chicago: Haymarket Books, 2019).

<sup>11</sup> David T. Mitchell, and Sharon L. Snyder, *The Biopolitics of Disability: Neoliberalism, Able Nationalism, and Peripheral Embodiment* (Ann Arbor: University of Michigan Press, 2018).

<sup>12</sup> Kristjana Kristiansen, Simo Vehmas, and Tom Shakespeare, eds., *Arguing about Disability: Philosophical Perspectives* (New York: Routledge, 2009).

<sup>13</sup> D. Christopher Ralston and Justin Ho, eds., *Philosophical Reflections on Disability* (London: Springer, 2010).

<sup>14</sup> David Bolt, *Metanarratives of Disability: Culture, Assumed Authority, and the Normative Social Order* (London: Routledge, 2021).

<sup>15</sup> Brian Brock, *Wondrously Wounded: Theology, Disability, and the Body of Christ* (Texas: Baylor University Press, 2020).

<sup>16</sup> Shane Clifton, *Crippled Grace: Disability, Virtue Ethics, and the Good Life* (Texas: Baylor University Press, 2018).

<sup>17</sup> I. Glenn Cohen et al., eds., *Disability, Health, Law and Bioethics* (London: Cambridge University Press, 2020).

determinant are seen.<sup>18</sup> Cultural studies attempts to bring about an epistemic change by rethinking disability.<sup>19</sup>

The beginning of the twenty-first century saw texts on disability that questioned the consistent problematisation of the disabled as the other in India. The complexity of disability was addressed in area-specific studies, such as Insa Klasing's<sup>20</sup> exploration of disability in rural India or texts concerning women and disability such as those by Anita Ghai<sup>21</sup> and Asha Hans and Annie Patri.<sup>22</sup> Interdisciplinary perspectives on disability discussing evolution, activism, policies, research, and accessibility also evolved; works by Nilika Mehrotra,<sup>23</sup> Renu Addlakha,<sup>24</sup> and Nandini Ghosh<sup>25</sup> are examples. Malini Chib's<sup>26</sup> disability and autobiography, and G. J. V. Prasad and Someshwar Sati's<sup>27</sup> disability and translation mark the evolving extensions of critical discourses on disability.

*Discourses on Disability* attempts to give new dimensions to disability studies in India. It brings together essays that discuss diverse topics ranging from theoretical premises that allow us to view the condition of disability from new perspectives to critical examinations of texts dealing with the lived experiences of persons with disabilities. This book attempts to erase the dividing line between critical knowledge and lived experiences,

<sup>18</sup> Jennifer Bartlett, Sheila Black, and Michael Northen, eds., *Beauty is a Verb* (Texas: Cinco Puntos Press, 2010); Tobin Siebers, *Disability Aesthetics* (Ann Arbor: University of Michigan Press, 2010).

<sup>19</sup> Katie Ellis, *Disability and Popular Culture: Focusing Passion, Creating Community and Expressing Defiance* (Farnham: Ashgate, 2015); Clare Barker, *Postcolonial Fiction and Disability: Exceptional Children, Metaphor and Materiality* (New York: Palgrave Macmillan, 2011).

<sup>20</sup> Insa Klasing, *Disability and Social Exclusion in Rural India* (Jaipur: Rawat Publications, 2007).

<sup>21</sup> Anita Ghai, *Rethinking Disability in India* (New Delhi: Routledge India, 2015).

<sup>22</sup> Asha Hans and Annie Patri, eds., *Women, Disability and Identity* (New Delhi: SAGE, 2003).

<sup>23</sup> Nilika Mehrotra, ed., *Disability Studies in India: Interdisciplinary Perspectives* (New Delhi: Springer, 2020).

<sup>24</sup> Renu Addlakha, ed., *Disability Studies in India: Global Discourses, Local Realities* (New Delhi: Routledge India, 2020); Renu Addlakha, *Deconstructing Mental Illness: An Ethnography of Psychiatry, Women, and the Family* (New Delhi: Zubaan, 2008).

<sup>25</sup> Nandini Ghosh, *Interrogating Disability in India Theory and Practice* (New Delhi: Springer, 2016).

<sup>26</sup> Malini Chib, *One Little Finger* (New Delhi: Sage, 2011).

<sup>27</sup> Someshwar Sati and G. J. V. Prasad, eds., *Disability in Translation: The Indian Experience* (Delhi: Routledge, 2020).



to effect layered discussions in disability studies. Each chapter hopes to broaden perspectives, raise questions, and understand silences.

Notions of disability are culture-specific. The way we think of disability is not preordained but created by people who want to retain power. If certain societies consider the mutilated body disabled, some other societies deliberately mutilate the body as an identity marker. Undoubtedly, the cultural translations of *disability* that evolve from a particular society are an extension of the popular understanding of ability. When the same patterning of social construction extends to other community rubrics such as religion, art, literature, or discourses within the family, it touches all domains of the episteme and concretises it. Kept away from knowledge production, the one-sided monologue of the normate reinforced the Manichean construction and defined disability as it deemed fit.

Historicising how contemporary societies engage with the idea of disability takes us to the beginning of European modernity in the seventeenth century. On the basis of the Enlightenment logic of critical binaries, European modernity categorised human lives into valid/invalid entities. The civilising mission of modernity rested on a discourse of ableism that constructed a “sanitised norm of human behaviour and appearance.” Their intolerance of biological and intellectual differences resulted in the othering of “non-normal” human beings. The disabled were confined to a “zone of exception,” exterminated or rehabilitated using medical practices. The project of modernity introduced new forms of human experiences, identities, and technologies under the garb of “civilisation,” resulting in a “tyranny of the norm.”<sup>28</sup> The dawn of the industrial society during this historical period further aggravated the predicament of the “disabled.” The production norms, time management, and discipline demanded of workers in the industries led to the elimination of the disabled from the workforce.

Foucauldian biopower emerges as “permanent, repetitious, inert and self-reproducing,” a normalising power that took over human bodies by applying itself to the “everyday life categories of an individual.”<sup>29</sup> Its acceptability was the logical end because it both masks and projects itself as indispensable. This intervention on the body is visible in its rejection of the disabled body and its mandatory surveillance that extends over rehabilitation, IQ tests, and medical classification. The disabled body is isolated not only by neglect or stigmatisation but also by invasive politics of care, corrective discourses, and the paternalistic gaze. Biopower takes

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<sup>28</sup> Lennard J. Davis, *The Disability Studies Reader* (New York: Routledge, 2013), 3.

<sup>29</sup> Michael Foucault, *History of Sexuality, Volume 1* (New York: Pantheon Books, 1978), 93.

life and extends self-governance into it. The lack of labour opportunity and policies that were instituted that have failed to materialise due to endless cost-benefit discussions are constraints imposed by the non-disabled majority on docile bodies. The steady removal of PWD to the margins is due to the lack of economic self-sustainability. Forced economic dependency on the family, compromised wages, denial of opportunity and having to answer recurring questions on one's productivity are consistent obstacles. As Vilas Shinde in "My Journey with Ataxia" reminds us, the financial instability should be addressed, as economic autonomy is the first step towards independence.

There is an indecisiveness in the relationship between postcolonial studies and disability. Though the former engages with the subjugated body, identity, and space, its theories have relegated disability to that of a representational tool. Disability is a frequently used metaphor<sup>30</sup> to describe colonial experiences of oppression. This shying away from disability concerns, rather than addressing them, viewing disability as a descriptive analogy instead of an active performative, needs rethinking. Disability theorists call for the need to decolonise disability where the absence of the colonial from Eurocentric writing<sup>31</sup> and the mapping of mental impairments to specific ethnic backgrounds should be addressed. These historical intersections to find the absent disabled in the colonial subject<sup>32</sup>—not just placing it in the nexus of modern industrial Europe—underlies postcolonial scholarship on disability.

*Discourses on Disability* highlights socio-cultural factors that trigger the "disability stigma" in India. Narratives from a person with bipolar disorder, another on the autism spectrum, and a third with locomotor disability scrutinise how it is to exist in a world conditioned by deep-seated cultural taboos. The chapters in this volume speak from the same locus of intersection as its predecessors in an attempt to recognise the systemic silence that still surrounds disability, particularly in India. The social imaginary of disability varies across cultures. Intersections of class, caste, and religion infuse it with their own narratives of stigma in India. This is further exacerbated by educational, economic, and geographical divides. Our challenge is to address this complex view of disability, to break the metanarrative of stigma that marks it, and focus on the self of the "disabled"

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<sup>30</sup> Shaun Grech and Karen Soldatic, eds., *Disability in the Global South: The Critical Handbook* (New Delhi: Springer International, 2016).

<sup>31</sup> Grech and Soldatic, *Disability in the Global South*.

<sup>32</sup> Anita Ghai, *(Dis)Embodied Form: Issues of Disabled Women* (New Delhi: Har-Anand, 2003).

person. What then evolves is an idea of disability that permits multiple meanings in understanding the term.

The book is an attempt to reread the texts as representation of the marginalised. The chapters on deaf studies and blind studies in India attempt to understand systems of thought existent in a disabled body, which manifest itself subliminally or forcefully through cultural interpellations. It rereads disability as a product of specific discourses and social processes, for arguably, within these domains of thought, culture has and still creates meaning regarding disability. Embedded within this space of a socio-historical reading, disability becomes the site where signifiers interact. The chapters on Kenzaburo Oe and Indian children's literature explore the politics of signification and also trace the dominant stereotypes ingrained in the reiterating representations of disability in culture. Disability in the posthuman age analyses how humans have moved beyond the confines of the body and crossed over to a techno-modified existence. Technological posthumanism transcends the boundaries of the purely human and investigates a space beyond and into the future of the species as an augmented and enhanced cultural entity. This human-machine interface has generated new ways of framing and understanding disability. To strike a distinct note, the chapter on disability theatre with special reference to India foregrounds how creative expression can assuage the lives of those who are physically challenged.

The liberating power of self-representation in disability life writing helps "imagine disability otherwise"<sup>33</sup> and has the potential to counter stigmatising portrayals through its narrative. Narration is also therapeutic for people such as Donna Williams, whose autism memoir helped bring her "chaotic life experiences on paper in chronological order."<sup>34</sup> Self-representation is a counter-discourse, an attempt to voice intense personal experiences without shame and to wean out of the overarching medical narratives that had previously disregarded subjective experiences. The narrative reconstructs pain or vulnerability, challenges the transgressions on the body politic, demands autonomy, and celebrates life. The "personal reflections" segments included are largely self-conscious autosomatographic narratives, written when the person is going through the disability, not after the cure. It helps to understand how each individual identifies themselves as a person with disability and how the body begins to act as a space for signification.

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<sup>33</sup> Linda P. Ware, "A Moral Conversation on Disability: Risking the Personal in Educational Contexts," *Hypatia* 17, no. 3 (2002): 143–72, <https://doi.org/10.1111/j.1527-2001.2002.tb00945.x>.

<sup>34</sup> Donna Williams, *Somebody Somewhere* (New York: Doubleday, 1994), 3.

The increasing amount of intersectional research in disability studies hopes to resist and extend the complexities of the able/disabled dichotomy, challenge singular narratives and capture discrete multiplicities. Primarily a feminist concern that emerged in the 1970s, intersectionality examines multiple subject positions that accrue over the socio-cultural ambit. Ideally, intersectionality encourages reciprocal connections between disciplines that push the self-marked boundaries of each systemic form of knowledge and emerges in the third space, benefiting from the varied insights gathered. The convergence of epistemes that inform disability studies includes animal studies, environmental humanities,<sup>35</sup> feminism, and so on. Another relatable perspective is that of aesthetics and disability, involving the representation of disability in art and the production of art by persons with disabilities.<sup>36</sup>

This volume has no rigid organisational framework. The chapters have been selected to address the fluidity of the identity of disability. The theoretical essays and first-person narratives help one understand the social context of living as a person with disability in India (essays on blind studies and deaf studies in India included in the book are unmediated first-person narratives). By adding first-person narratives, this volume accepts that each person living with a specific condition is unique. The chosen narratives are not necessarily representations of the others of the same condition. Neither sweeping generalisations nor metanarratives are endorsed. The attempt here is to contextualise first-person narratives to remind of the lived experiences behind the theoretical standing.

The aim of the book is to envision an inclusive world undeterred by hegemonic notions of normality.<sup>37</sup> The challenge here is to bring together concerns that arise not by just being aware of a particular physical or mental condition, but by reaching a state of unbiased and non-condescending acceptance of any individual with “impairment.” The book seeks to explore the archetypal cultural history of subversion and stigma, rereading the representational politics of disability in niches of cultural collectives. It studies specific paradigms of thought with reference to individual disabilities in blindness, deafness, learning disability, and the like.

Meant for the committed academic and the lay reader alike, this book is a panoply of readings on the many aspects of disability. The carefully curated articles discuss specific theoretical positions, suggest

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<sup>35</sup> Anthony J. Nocella II, Judy K. C. Bentley, and Janet M. Duncan, eds., *Earth, Animal, and Disability Liberation: The Rise of the Eco-Ability Movement* (Bern: Peter Lang, 2012).

<sup>36</sup> Addlakha, ed., *Disability Studies in India*.

<sup>37</sup> Davis, ed., *The Disability Studies Reader*, 10–12.

policy changes, elaborate on practical aspects, and highlight the personal side. The advanced reading list provided makes the book a helpful resource for furthering disability studies.

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# CHAPTER ONE

## INTERVIEW LIVING WITH SCHIZOPHRENIA AND BIPOLAR DISORDER: THE JOURNEY OF A MIND

### IN CONVERSATION WITH ARTIST ANU KALIKAL

There are always colours around Anu Kalikal. One would be staggered by their ebullience. She sits surrounded by her drawings on the walls. The book on her lap carries her doodles, and I can see canvases neatly lined up waiting for their turn of coloured rain. Anu is in her late thirties and is an artist by profession. She has a rich guffaw, peers through her round glasses that seem larger than her face, and has a curious glint in her eyes when anything catches her attention. She is clinically diagnosed as having schizophrenia and bipolar disorder, and that to her is what makes her different. In the following conversation between the editor and Anu Kalikal, she speaks about her condition, her art, and spaces between.

*1) You are an established abstract artist. Do you think your condition has coloured your art?*

I have always registered everything with colour—a memory, a situation, even decisions. I started drawing and colouring at a very young age. Even as a young child, I drew conceptual art that was not easily understood by others. My condition has contributed to my art, but it has taken years of therapy, medication, constant practice, and encouragement to be where I am now as an artist. I believe I am a better artist now, but it was not easy because with my condition came with much internal confusion, a state of mind that was difficult to calm down. I often gave up and felt left behind. But over the years, I have realised that my condition has given me a perspective that others do not have. When I draw or paint, it flows from the inside. Every

inch of who I am, including my confused mind, emerges. There are days of confusion, and there are days of utter clarity—the drawings will vary accordingly. It is just a matter of practice, patience, and self-encouragement.

*2) The thick and thin of life has undoubtedly grazed you in ways much more than usual. You have braved great odds to reach here. Will you speak about your journey? Has it been all pain or was the pain interlaced with hope?*

Life is not easy being a person with bipolar-schizophrenia. I have many limitations that I had to come to terms with. My journey is definitely with obstacles, yet I feel these obstacles have made me a braver person. When I completed twelfth grade, I was sure I wanted to be an artist, but since no one in my family took art as a profession, I was guided to do my undergraduate degree in English literature. I did not object as I loved to read books and write. However, during those years, I became more convinced I wanted to be an artist. I had no one to guide me on how to become one, and as it was the early stages of my illness, I was physically and mentally getting exhausted. I was unaware of the medical diagnosis since my family had no precedent. Life took a turn and I became confused and broken.

Somehow, I ended up in front of a psychiatrist and from then on, I have been slowly fixing my life. The word *fixing* meant for years and years of mental pain, loss of memory, physical disabilities, and a young person not being useful to anyone. Those were years of utter despair. My desire to be an artist was washed away during the initial years of treatment. Against my counsellor's advice, I married, after confiding in my future husband. He was willing to stand by me. I must admit that I began trying to get better just for him. Whenever I woke up in the morning confused and lost, unable to remember even the silliest of things, I would still convince myself to remain positive and continue taking medications for his sake. I wanted to get better for him. I believe everyone should have at least one person who believes in the slow process of recovery.

I also had friends who kept encouraging me. There were months when I did nothing. Sometimes, even years went by with me doing nothing. When I lost hope, my husband, close friends, medication, and therapy continued to give me hope. Over the years, I learned to live with the tremors in my hands, tried to draw and paint again, and found methods that would help me with decisions that would appear easy for everyone else but mind-racking for me. I practised drawing more and tried to take care of myself more. It was challenging because whenever I tried to concentrate or follow a discipline, I would have severe tremors that would devastate me both mentally and physically. My doctor would always tell me that every patient is different, so never compare. I stopped talking to myself as it increased the



chances of entertaining the voices in my head, and I started concentrating on drawing more and writing more. I learned to control my mind, especially the mood swings and the crowded voices inside my head. It is not easy to convince yourself when you are low that it is okay to feel low, because it is an illness and not a character flaw. However, I am happy that I did not stop trying. I often have relapses and cannot keep a job, yet I know life is beautiful and worth these ups and downs.

*3) Every individual emerges and grows through conflicts that make or break you. Can you talk about the challenges you face with your condition?*

There are many challenges I face—visible and invisible. The visible challenges are a lack of energy, the ability to keep a proper job, live a disciplined life, complete deadlines, or focus on anything that demands concentration and dedication. The invisible challenges are the disinterest to socialise at times, finding it difficult to follow conversations like others, trying to understand whether a memory you remember is real. Sometimes voices talk inside you continuously for minutes or hours at length, and images seem to pounce out from anything like a pattern in a carpet or from the bushes or even from cloud formations.

Simple everyday decisions about what to wear or eat are difficult. I have to fight to convince myself that I have closed the door and still keep checking it umpteen times. Change, too, is difficult. Trying to adjust to any sudden alteration in routine is tough. I prefer to be told beforehand what to expect within a day, as otherwise, I tend to have anxiety attacks that lead to tremors and palpitations. I have learned over the years to live with people again by self-introducing various methods that help me cope with decisions and anxiety.

It was my dream to do my masters in fine arts—I loved reading about artists, their methods and everything in the magnificent world of art. But I underwent a disconnection between my thoughts and speech, which was the last straw, and I eventually withdrew from the course. It hurt me to give up what I wanted so badly to learn. I felt it was the end of much, but a dear friend reminded me that this was just the beginning—of something more beautiful. It took me years to understand what she meant. But I am glad she was able to convince my broken heart then. Many people refuse treatment and lose hope because we cannot see over the worst times.

Sometimes there is nothing but darkness. My mind becomes home to despair and all I can register then is a desperate need to stop the pain seething in the mind, body, and soul. I would say I managed school and college only through the love and care of certain people. I think the only

thing that matters is love in this world. And that is an eternal truth that goes beyond any scientific discovery.

*4) Our story is what we have made of ourselves. How did you manage to tide over the difficulties of growing up?*

I think it was in my tenth grade that I first realised I had difficulties in concentrating. At the end of the year, I realised that I could not read a text beyond the first two pages. Every time I tried to study, the voices in my head would start to play a game, and I could not come out of it. I was not aware that I needed medical treatment for this game-playing. My family thought I was just an over-imaginative kid who liked to play make-believe games a bit more than others of my age. I also had severe headaches that would make my jaw and bones hurt, which left me in its clutches for days. I tried self-treatment, took painkillers that were readily available—as quite often, ENT doctors or general physicians could not find any reason for my persisting headaches.

When I entered college, there was a whole realm of change, and there I slowly started to fall apart. Yet, I somehow managed to clear my undergraduate programme. My doctor once told me that she was very impressed with how I managed to pass the course with my extremely poor concentration abilities. I slept very little, could not digest food, began to vomit blood, and had blood in my stool. I had become a shadow of who I was. My family was in another country and I was all alone. I survived those days purely because of a dear friend who stood by me through the bad days as I began the treatment for bipolar mood disorder and schizophrenia.

*5) Since schizophrenia and bipolar are invisible disabilities, do you think you faced the brunt of it more? Do you think increased awareness of your condition would have brought more understanding?*

I was diagnosed while I was living in South India. I realised that this illness is spoken about significantly less in India. It is still considered as a curse. Families hide or hush the person undergoing it in places where “normal” people would not come in contact with them. That it is an invisible disability adds to the difficulty of accepting the person who has it. When I was first brought in front of the doctor for diagnosis, she asked me some questions, which I answered well. Later she explained how it became easier for her to help me. Sometimes this clarity in self-expression prevents others from believing that you have a mental illness. Their instinctive response is, “How could it be possible? She is definitely acting.” Let me tell you, hearing that hurts!

6) *Did you at any point of time feel like screaming out against the silence in India surrounding mental health?*

It is not easy to talk about the mental pain one is going through. It is difficult for me to even answer these questions for this interview because I have to try very hard to concentrate on answering. A better understanding of this condition would help, but in India, where superstition, tradition, caste, and poverty exist, I am not sure how much education regarding such conditions can open eyes. If it is a broken arm, you can put it in a sling, or do chemotherapy if it is cancer, but a mental illness, even though the person is from a well-educated family, is still considered a burden and a shame, probably because, I feel, India is too deep in its own beliefs. There are, of course, hospitals to help us, but a considerable number of people kill themselves simply because of the lack of acceptance. The single word *acceptance* means the world to a person with this condition. Each day we wake up hoping we are part of society and not tagged as an untouchable.

India is trying to educate its people regarding mental health, but I feel there is still a gap. I will not call it silence because there are attempts to reach out, help, and educate. However, there is still a wide gap and that is the reason for suicides among persons with such illnesses. Regarding bipolar and schizophrenia, I feel there is silence, the type of silence that makes a sound but cannot be heard. This silence is called ignorance. I have faced this ignorance in the form of fear, even from people in the medical field itself. While I was trying to recover, I sometimes found medical staff who feared us. They came on duty only because they were appointed there. They do not realise that we have feelings too and can read and understand their reactions. Recovery is difficult, especially when you live in a country like India.

7) *As an artist you have spoken your heart and mind to the world. Would you suggest art as a therapy for others?*

Art is a beautiful medium for those undergoing depression or related issues. It eases the brain and allows stress to flow out through art. Many well-known institutions use art as a therapy. I definitely would suggest it for others like me.

8) *You have come a long way sailing against all odds. What formed your view of life?*

I believe everything in life is temporary. Happiness, sorrow, sickness, health... everything in life has a short span. This view helps me when my polarities hit me. When the voices in my head overcome me, I control and subdue that moment or hour by repeating, "this too shall pass." It makes pain bearable. There is no ultimatum in anything. Just a faith that everything moves on.

## CHAPTER TWO

# DISABLED LIVES AND SYNERGISTIC INTERVENTIONS

MAHIMA NAYAR AND SRILATHA JUVVA

Disability as a heterogeneous construct escapes the attention of all those without a disability, thus creating disempowering and spirit-breaking environments that perpetuate stigmas and misconceptions, and advance “othering.” In this chapter we will explore how people with disabilities deal with the intersections of life-diminishing practices, disempowering cultural norms, and disabling systems that play out in their everyday lives. The foundational principle underpinning this chapter is that all human beings have inner capacities that are manifested in everyday life; however, they are interrupted by life-diminishing systems and cultural norms, thus forming a barrier that the person with a disability must navigate through life. Using data from the field and drawing on the Conscious Full Spectrum Response Model founded by Monica Sharma, the authors will explicate how when disempowering systems and cultural norms are interrupted, the goals of the Incheon strategy and the Sustainable Development Goals will be realised.

### **Introduction**

In the ideas surrounding Sustainable Development Goals (SDGs), it is recognised that including disabled people in development processes is essential to ensure that no one is left behind. However, the myths and misunderstandings surrounding disability have created situations which have meant many disabled persons are left behind in many spheres of life. According to the UN flagship report on disability, persons with disabilities are more likely to live in poverty than persons without disabilities due to barriers in society such as discrimination, limited access to education and

employment, and lack of inclusion in livelihood and other social programs.<sup>1</sup> Available data show that the proportion of persons with disabilities living under the national or international poverty line is higher than, and in some countries double, that of persons without disabilities.<sup>2</sup>

It is estimated that approximately 80 per cent of the world's more than one billion persons with disabilities reside in a developing country, frequently in poverty.<sup>3</sup> Accordingly, "Disability is a development issue because of its bidirectional link to poverty: disability may increase the risk of poverty, and poverty may increase the risk of disability."<sup>4</sup> Even though there have been many new developments, a lot remains to be done. Because of restricted access to education and employment, people with disabilities and households with disabled members remain disproportionately poor. Research shows that in many countries, a disability and development gap is growing: unless people with disabilities are routinely included in development efforts, their socioeconomic status often remains static while the status of their non-disabled peers' surges ahead.<sup>5</sup>

Such conditions could not be addressed unless issues related to disability were included in the larger developmental goals of the world. After the passage of the Convention on the Rights of Persons with Disabilities (CRPD), international disability activists lobbied the UN to ensure that disability-specific goals were incorporated into Millennium Development Goals (MDGs). Although people with disabilities went unmentioned in the MDGs, the SDGs include disability throughout, in keeping with the CRPD. SDGs recognise the importance of redressing inequities experienced by vulnerable and marginalised groups and communities (including persons with disabilities) in high-income nations.

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<sup>1</sup> United Nations, "Disability and Development Report: Realizing Sustainable Development Goals by, for, and with Persons with Disability," Department of Economic and Social Affairs Disability, New York, 2018, <https://social.un.org/publications/UN-Flagship-Report-Disability-Final.pdf>.

<sup>2</sup> Ibid.

<sup>3</sup> UN General Assembly, "Transforming our World: The 2030 Agenda for Sustainable Development," Sustainable Development Goals, Knowledge Platform. United Nations, 21 October 2015, <https://sustainabledevelopment.un.org/index.php?page=view&type=111&nr=8496&menu=3>.

<sup>4</sup> Monica Pinilla-Roncancio, "Disability and Poverty: Two Related Conditions; A Review of the Literature," *Revista de la Facultad de Medicina* 63 (2015): 113–23, [doi.org/10.15446/revfacmed.v63n3sup.50132](https://doi.org/10.15446/revfacmed.v63n3sup.50132).

<sup>5</sup> N. Groce and M. Kett, "The Disability and Development Gap," Working Paper Series no. 21 (London: Leonard Cheshire Disability and Inclusive Development Centre, 2013).

Even though such persons reside in high-income countries, their experience of relative poverty, disenfranchisement, and disadvantage remains unjust. Their governments need to be held accountable, and accordingly they need to improve domestic policy and law in line with their SDG commitments.<sup>6</sup> The Incheon Strategy builds on the CRPD, the Biwako Millennium Framework for action, and the Biwako Plus Five towards an inclusive, barrier-free, and rights-based society for persons with disabilities in Asia and the Pacific. It is intended to enable the Asian and Pacific region to track progress towards improving the quality of life and fulfilling the rights of the region's 650 million persons with disabilities, most of whom live in poverty. Its goals include reduction of poverty and enhancing work and employment prospects, social protection, and ensuring disability-included disaster risk reduction.

The Incheon Strategy and SDGs promote national leadership in meeting specific development goals, taking into account local capabilities and realities. Implicitly in the call to “leave no one behind” and explicitly by including people with disabilities in a series of specific targets and indicators,<sup>7</sup> both have taken into account the needs of disabled people. They are also based on respect for human rights, and take a people-centred and gender-sensitive approach to development. The international agenda also has to consider the ground realities of different countries. There is a great onus on low- and middle-income countries to step up and work hard to overcome the extraordinary legal, policy, social, structural, environmental, socio-cultural, and other entrenched barriers (including those related to the human right to health and health's underlying social determinants) for persons with disabilities.<sup>8</sup>

The challenge to fulfilling these goals has also been related to different understandings of disability in various parts of the world. It has been difficult to define and theorise disability, and any effort to understand disability as a unitary experience has been rejected.<sup>9</sup> Different societies have understood disability in different ways and impairments are interpreted in

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<sup>6</sup> Paul Lucas, Kanie Norichika, and Nina Weitz, “Translating the SDGs to High-Income Countries: Integration at Last? IISD Reporting Services” (17 March 2016), <http://sd.iisd.org/guest-articles/translating-the-sdgs-to-high-income-countries-integration-at-last/>.

<sup>7</sup> Nora Groce, “Global Disability: An Emerging Issue,” *Lancet Global Health* 6, no. 7 (2018): E724–25, [https://doi.org/10.1016/S2214-109X\(18\)30265-1](https://doi.org/10.1016/S2214-109X(18)30265-1).

<sup>8</sup> Pinilla-Roncancio, “Disability and Poverty.”

<sup>9</sup> Nilika Mehrotra, *Disability, Gender and State Policy: Exploring Margins* (Jaipur: Rawat Publications, 2013).