

The London School of Economics and Political Science

Psychosocial disability activism in India:

Knowledges and practices towards justice, from the margins

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A thesis submitted to the Department of Methodology of the London School of Economics and Political Science for the degree of Doctor of Philosophy,  
London, March 2025

## **Declaration**

I certify that the thesis I have presented for examination for the MPhil/PhD degree of the London School of Economics and Political Science is solely my own work other than where I have clearly indicated that it is the work of others (in which case the extent of any work carried out jointly by me and any other person is clearly identified in it).

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## Acknowledgements

A hundred thousand words over four and a half years and I think this is the hardest bit to write. There are so many conversations, books, movies, songs, poems, hugs, and art that have made this possible. And so many many people. How do I even begin to acknowledge all the people and the relationships that have made this PhD, that have made me?

I first met Flora Cornish in October 2019 to discuss the possibility of doing a PhD under her supervision. We had a slight miscommunication about the time and spoke while walking at a brisk pace to the tube station. I was not sure what to make of this rushed conversation, but I sent her my draft proposal. A few days later, I received the most thoughtful, engaged, and responsive comments on it. I felt seen and read and encouraged, something she has never failed to make me feel in the last five years. LSE was not my first choice of universities, but I cannot thank my stars enough that I ended up here, because that meant that my supervisor was Flora. When I first started this thesis, I was fully prepared for a journey that would be marked by several emotional breakdowns, constant personal crises, and the never-ending task of trying to survive the university. And while it was not always easy or smooth, Flora has had my back every single moment. They say that supervisors make or break your PhD, and it is not an overstatement of any sort to say that Flora made this PhD. Unlike most students, I have been known to say that I would start another PhD next year if I could find someone to fund it. It's because of how safe I have felt under Flora's supervision.

I met Sara Salem a bit later, although her radical reading social media page made me feel like I had known her for a long time. Somewhat intimidated and a bit confused about the role of a second supervisor, I was apprehensive about working closely with her. That vanished very quickly. Like Flora, Sara has unflaggingly read every draft, even the cringeworthy ones, and sat through my long rambling ideas in many supervision meetings. She has gone above and beyond as a second supervisor, and I am so grateful to her.

I value Flora and Sara's engagement with the work. They are brilliant academics, their work is inspiring, and they have enabled my engagement with so many new ideas and concepts. But far more importantly, they have always extended kindness towards me, and through their actions, I learnt ways of enacting care and support in a world which does not reward kindness. I could not have made it to where I am without them.

I have so much to say and so few words to truly express how much of an influence my brilliant sister, Akanksha Mehta, has had on me. I grew up with her literally and I grew up with her

politically. She has been my go-to person when I have questions about some academic theory, the latest Bollywood gossip, or song/movie recommendations. But more than anything, she has shown me what it meant to build community, to open yourself and your home to friends and lovers, to cook and feed myself and others as an expression of love, and so much more. In the last few weeks before submission, she called me every single day to check in, to send me memes, to make sure I was eating well, and to reassure me that this thesis was something I should be proud of. I don't know what I would do without her in my life.

My parents, Nalin and Binty, have always told me that I can do anything I wanted to. Through the worst of my madness, they protected me, supported me, and did not let me fall off the planet. They have repeatedly told me how proud they are of me, whether I was doing a PhD or just trying to exist. I would not be the person I am without them. A special shout-out to my mom's hilarity in the last few weeks before submission. She reminded me over and over again "*baathi nikal gaya, poonch baaki hain*" i.e., the elephant has passed, only the tail is yet to pass. Thank you for that encouraging, and slightly disturbing, reminder.

No one has witnessed (and experienced) the ups and downs of this process more than my partner, Michael Moss. In July 2019, when I was still figuring out how and where to apply for PhDs and increasingly panicking about the prospect, I remember his gentle (and somewhat anxious) questions about the process while we sat in Brockwell Park on a sunny day. He was there when I applied, when I got funding rejections from other universities, and when I got the studentship at LSE. He has supported me through my struggles with longCovid, with the grief of the second wave in India, with my despair over the burning world. Five years later, he has painstakingly read every single word of this PhD, pushing me on the substantive content, catching the little errors, and expressing his frustration with my tendency to write 100-word sentences. More than this ridiculously boring task of reading, he has extended a quiet sort of support, the almost unnoticeable acts of kindness—the glass of water that mysteriously appears at my desk, the little hugs and jokes, my personal cheerleading potato, the favourite foods which suddenly find their way into the kitchen when things were particularly hard. And like my parents, he too has repeated his favourite supportive phrase: "how do you eat an elephant? One bite at a time".

(Seriously, why is everyone bringing elephants into this!?)

There are some people who have become so much a part of my life, I can almost feel them in my bones. Wasif Shaikh and Fatma Khan are two such people, *mere jigad ke tukde*. I met Wasif in 2004 when he gave me his sweatshirt in school because I was cold. And every day since, he has

been my rock. I can't imagine a world without him. I can't remember exactly when I met Fatma (I think it was in 2019) but I cannot imagine a time I did not know her. I have a postcard on the pinboard on my desk which says, "I am half agony, half hope". Fatma has nurtured the parts of me that are all hope. She submitted her PhD a few months before me, and we have talked about our work, our worlds, our lives for hours and hours. Fatma's love, her dreams, her thoughts, and her struggles are all over this thesis.

My friend, Liat Davis, has never flinched from the darkness in me. She has always made space for me to be my maddest self and for that I will always be grateful. A fellow PhDer a year ahead of me, she let me witness her last few months and prepared me for mine. Thank you for everything!

So many people read a chapter or talked through some aspect or another of this thesis with me. A big thanks to China Mills, whose work and friendship rescued me from the wild epidemiological and oh-so-frustrating world of global mental health and shaped so much of my thinking about madness and disability. She read through many chapters and even brainstormed ideas for the title. I had briefly considered doing my PhD under her supervision but decided to keep the friendship instead. And every time we meet for coffee, a drink, or a laksa, I am so glad that I did.

Niharika, *meri jaan*, thanks for reading through my chapters and helping me understand the point I was trying to make and just being your amazing self. Thanks to Jo, Saumya, and Krupa for reading parts of this thesis and for being in my life. Your friendships hold me together. *Tumhare bina kuch nabin hota!*

I lacked the courage to send drafts to some people, but they have been equally important in shaping my writing. Jayasree Kalathil is one such dear friend, and I cannot thank her enough for every conversation I have with her. I have learnt so much from her, from growing squash, the types of fungi, the politics of literary translation, and of course madness.

I don't know how to fully express what Stan Papoulias has done for me. I look at them, and I truly cannot understand how someone like them exists. They have taught me so much, but more than anything, they have taught me how to let kindness live alongside rage at the world. I see in them a deep hurt and despair at the state of the world, and equally an absolute refusal to give up.

[Thank you also to all the horrible people who provided me with that extra motivation—spite—when love and care wouldn't suffice. To the head of department from a decade ago who told me that my mentally ill brain could never handle higher education; the abusive boss; the relative who

casually dropped into conversation that all disabled people were a drain on society; the doctor who wouldn't believe me because mad women always have something going on. Spite is a powerful motivator, so thank you. May your socks always be slightly damp.]

A shout-out to the whole Methodology department. I have not been able to be as present as I would have wanted in the department. I have missed so many drinks and hangouts but my fellow PhD students and everyone else in the department never let me feel excluded. A special thank you to Camilya, who keeps us all going and whose warmth and efforts always make me smile. My peeps—Nancy, Poorvi, Islam—have been a treasure trove of practical tips, emotional support, and perspective (“it’s just a PhD, nothing lives or dies on it”).

I will never know what good fortune brought Alberto Vásquez and me together, but I am glad it did. Thank you for waiting so patiently for me to finish this PhD and I can’t wait to start work with you on Mad Thinking.

And finally, I am forever indebted to all my interlocutors, for their time, their knowledge, their trust, and their amazing work. My name might be the only one on this thesis, but they are the ones who made this possible.

## **Abstract**

This thesis employs intersectionality and disability justice to inform a study of how activists with psychosocial disability in India understand and ‘do’ psychosocial disability. It responds to key critiques of existing literature: the absence of an intersectional lens in disability activism; the emphasis on a legalistic rights-based approach in disability; the dominance of the global North in framing the concept of ‘psychosocial disability’; the positioning of persons with psychosocial disability as objects rather than epistemic actors.

My research draws on crip and critical disability theorisations as well as my own experiences as a Mad disabled researcher to analyse interviews with activists occupying multiply marginalised socio-political positions, including psychosocial disablement, in India. The analysis of 25 interview texts reveals that at the margins of the mainstream psychosocial disability activism, activists employ ‘psychosocial disability’ as a radical lens to explain, understand, and ultimately challenge oppressive structures such as casteism, fascism and militarisation, the criminal (in)justice system, and cisheteropatriarchy. They grapple with and attempt to resolve the tensions between abolition and reform in ways which bring together radical dreams and everyday practices of care and community-building while simultaneously navigating and negotiating with deeply broken medico-legal regimes. The demands of neoliberalism and fascism within movements present unique challenges for disabled and marginalised activists in India, and they undertake innovative ways to create spaces of liberation within and at the margins of a mainstream movement.

The thesis contributes to disability studies and social movement literature by providing an example of what an intersectional liberatory practice can look like, the commitments that inform and animate it, as well as the struggles, challenges, and contradictions which shape it. This thesis invites activists and scholars embedded in movements of all kinds to bring a crip perspective on organising and resistance.

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### **List of acronyms and abbreviations**

AFSPA – Armed Forces (Special Powers) Act 1958

BJP – Bharatiya Janata Party

CAA – Citizenship Amendment Act

CDA – Critical Discourse Analysis

CDS – Critical Disability Studies

DBA – Dalit Bahujan Adivasi

DisCrit – Disability critical race studies

DPO – Disabled Persons Organisation

ENUSP – European Network of Users and Survivors of Psychiatry

FCRA – Foreign Contribution (Regulation) Act 2010

IDA – International Disability Alliance

LSE – London School of Economics and Political Science

MGMH – Movement for Global Mental Health

MHCA – Mental Health Care Act 2017

NGO – Non-Governmental Organisation

NOUSPR – National Organisation of Users and Survivors of Psychiatry Rwanda

NRC – National Register of Citizens

PhD – Doctor of Philosophy

PWD Act – Persons with Disabilities (Equal Rights and Full Participation) Act 1995

REC – Research Ethics Committee

RPD Act – Rights of Persons with Disabilities Act 2016

RSS – Rashtriya Swayamsevak Sangh

SDGs – Sustainable Development Goals

SHG – Self-help Group

UN – United Nations

UNCRPD – United Nations Convention on the Rights of Persons with Disabilities

WHO – World Health Organisation

WNUSP – World Network of Users and Survivors of Psychiatry

## *A prelude*

*When I wrote the proposal for this PhD, I was several decades removed from my first interaction with the mental health system. I was several years into understanding my experiences through a socio-political lens and utilising that understanding to challenge current knowledge generation regimes. At the same time, I had perhaps not yet engaged with disability movements and activism in an extensive manner.*

*In the months prior to starting this PhD, the world was engulfed in the Covid-19 pandemic. I engaged in discussions about what the pandemic meant for fieldwork, what it meant for research, for pedagogy. All important questions. In the early days of the pandemic, I keenly followed disabled activists on social media and elsewhere as they discussed working from home, the state and indeed the public's willingness to let them die, the worlds opened up by their ability to attend events from home and so much more. I cared about these issues, but I think I was somewhat removed from. That was until I was struck with longCovid.*

*My body joined my mad disabled mind and like so many others before and with me, my bodymind held and carried pain, loss, and grief.*

*So, I started this PhD navigating the world as not only psychosocially disabled, but with a disabled body too. This threw up logistical and practical challenges, many of which continue to haunt my life—how to engage in academic thought through brain fog, how to develop friendships while constantly sick, how to keep up with deadlines while dealing with a bodymind that refuses to cooperate. In the early months of the PhD, I often thought how terrible the timing was. But with time, I also realised that in some ways, it was fortuitous. I was processing this new relationship with my body and society at the same time I was reading disability theory. As I read articles and books about critical disability studies, crip theory, and disability justice, I was often reminded of the much-cited bell hooks (1991) quote:*

*“...I came to theory because I was hurting—the pain within me was so intense that I could not go on living. I came to theory desperate, wanting to comprehend—to grasp what was happening around and within me. Most importantly, I wanted to make the hurt go away. I saw in theory then a location for healing” (hooks, 1991, p. 1)*

*And I did find healing. I found in some corners of scholarship echoes of what Leah Lakshmi Piepzna-Samarasinha (2018) writes about disability justice, “that it is simultaneously beautiful and practical. Poetry and dance are as valuable as a blog post about access hacks” (p. 23). I always knew, but was reminded powerfully, that survival, resistance, and creating knowledge is a collective endeavour both in an everyday sense—small acts of care between friends, words and actions of support from my supervisors—and on a larger scale—dreaming up new worlds and building them. The people who have embodied the values of disability justice span mentors I have never met who I know only through their work and others much more proximate to my everyday life.*

*I finish this thesis with a keen, felt, and visceral knowledge that this ground was not built by me alone, but like everything else, it is a collective project spanning time and geography. This PhD is a part of that collective project, and I hope that I wrote it in a way that truly reflects that.*

## **I. Introduction**

People have always experienced distress and unusual experiences. We have been blessed and cursed with visions and voices. We have been formed and re-formed as seers and clairvoyants, as mentally ill patients, as witches and dangerous criminals, as paupers and lunatics, as pitiable objects of charity, as weak and vulnerable, as users of psychiatry and equally its survivors, as disabled, and in a thousand other ways. We have been lobotomised and locked up to protect us from ourselves and to protect society from us. And we have always found each other in the unlikeliest of places. In the halls of an asylum, in passing on the street, in online forums, in peer groups, and through accidentally intimate conversations at gatherings. There are very few times I feel comfortable using declarative sentences and there are many things I am uncertain of. But one thing I know is that we have always existed, survived, and sometimes thrived. We have told ourselves and others our stories. Our stories are stories of subjugation and oppression, but they are also stories of survival and resistance. This thesis is a continuation of that long tradition. It is concerned with another way to understand our lives—psychosocial disability. Psychosocial disability is not a new phenomenon; it is just one more way to understand our lives and the world, to come together, and potentially mobilise a group of people who have always existed.

### **1.1 Writing for: the stakes, the researcher, and the pillars of this thesis**

As I started this thesis, I believed that psychosocial disability activism, in and of itself, was worthy of examination and exploration. Psychosocial disability, as a concept, has been taken up by activists in the global South<sup>1</sup> as a way to counter/challenge the dominance of biomedical models and create different ways to understand personal and collective experiences of distress and unusual/alternate experiences.<sup>2</sup> Given the increasing number of people being diagnosed with ‘mental illnesses’ and psychiatrised as a consequence, the spread of biomedical models to the global South through global health and global mental health networks, and the ensuing erasure

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<sup>1</sup> I understand the global South not as “a geographical entity but rather as an analytical category in the sense that most Southern societies have experienced colonial and post-colonial and/or imperial epochs in their histories.” (Fadaee, 2017, p. 47). As such, the term global South “references an entire history of colonialism, neo-imperialism, and differential economic and social change through which large inequalities in living standards, life expectancy, and access to resources are maintained.” (Dados & Connell, 2012, p. 13)

<sup>2</sup> Throughout the thesis I use the words distress or unusual/alternate experiences to reframe experiences which are often psychiatrised and described using medicalised language such as mental illness, mental disorders, mental problems, and/or diagnoses. It is important to note that not all people experience unusual/alternate experiences as distressing. Rather they may experience them as a form of joy or spirituality.



of non-medical understandings of distress and unusual experiences, I believed and still believe that the stories of those who resist these trends through collective action need to be told.

Although psychosocial disability emerged as a way to undermine the universalist and individualised models of psychiatry, the actors and organisations who embrace/create it are subject to the forces of global capitalism which shape and sometimes co-opt activism in its image. In the years before I started this project, I saw and heard a singular story of psychosocial disability, one that often excluded the lives and knowledges of people and communities who live at the intersection of oppressions. As any PhD student knows too well, I have been asked by friends, family, and strangers alike to say in one sentence what my project is about. I went through various iterations of that one sentence, and this is what I have landed on—I look at how politicised understandings of mental health and disability emerge from intersectional and lived experience-based activism in India.

My thesis extends what psychosocial disability means and could mean. It contributes to and expands critiques of mainstream disability studies and disability rights frameworks, their implementation, politics, discursive and material circuits. My research and analyses are aligned with activism and scholarship which incorporate political readings of mental health and disability. Too many of us in and around activism are burnt-out, ill, exhausted, despairing, disconnected from our bodies and minds, struggling, and in a state of crisis. How could we not be in the face of climate catastrophes, fascism, genocide, pressures of capitalism, isolation, and the incredible pressure of caring in a world that punishes those who care. The knowledges of my interlocutors who are ‘doing’ activism in ways that accommodate their mad disabled bodyminds<sup>3</sup>, resonate with all justice-based activism.

I approach this thesis and all it contains from particular understandings of knowledge and knowledge generation. First and foremost, informed by approaches which understand social actors as epistemic actors, I too position those deemed ‘mad’, i.e., people who have experienced mental ill-health and mental health systems as epistemic actors (Escobar, 2009; LeBlanc & Kinsella, 2016). I approach psychosocial disability as an identity, concept, and framework generated by and through the epistemic work of persons with psychosocial disability. Second, I make these interventions with, and not about, the knowledges generated in activist movements. For me, as it is for others, movements are sites of knowledge creation and theoretical

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<sup>3</sup> The term ‘bodymind’ rejects the division between body and mind and understands that “mental and physical processes not only affect each other but also give rise to each other—that is, because they tend to act as one, even though they are conventionally understood as two” (Price, 2015, p. 269).

development, and activists are knowledge generators (Casas-Cortés et al., 2008; Cox & Flesher Fominaya, 2009; Icaza & Vázquez, 2013). As a psychosocially disabled researcher working with/alongside/from the psychosocial disability settings in India I foreground, I see this project as a small part of the body of epistemic work of psychosocial disability activists. Finally, I understand that knowledges from marginalised locations enable us to make “the politics of knowledge and the power investments that go along with it visible...” (Mohanty, 2008, p. 511). For me, this means centring the global South, mad disabled folks within the global South, and finally, privileging those who live at the intersection of multiple oppressions. This epistemological stance, which I will explicate further in the next chapter, underlies the methodological, conceptual, and analytical choices I made.

I interviewed twenty-five activists within psychosocial disability movements. Most, if not all, of my interlocutors place themselves in other movements along with disability. They embody and focus on queer, trans, feminist, anti-Hindutva<sup>4</sup>, and anti-casteist<sup>5</sup> activism. Their positionality and insights provide an analysis of not only how psychosocial disability is constructed and ‘done’ with respect to external institutions but also within the mainstream psychosocial disability movement. Ultimately, I argue that psychosocial disability at the margins is much more than a bounded identity and a category. Rather, it is employed as a radical lens to disrupt singular definitions, understandings, and mobilisations of the concept. In this way, psychosocial disability is an ongoing practice of negotiation between our radical dreams of justice and the realities of living with systems of violence. Its practice is partial (never comprehensive), provisional (always a work in progress), particular (always contextual), and plural (containing multitudes).

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<sup>4</sup> Hindutva, also known as Hindu Nationalism, is a movement that traces its roots to the 1920s with the formation of the Rashtriya Swayamsevak Sangh (RSS). It has variously been categorised as religious nationalism, cultural nationalism, authoritarianism, majoritarianism, Indian fascism, and Brahminical fascism. Some scholars understand it as a fascist mass movement which has gained state power. Since 2014, when the Bharatiya Janta Party (BJP), the political wing of the RSS, won electoral power and Narendra Modi became prime minister, Hindutva’s popularity and power has increased significantly. One of Hindutva’s central assertions is that India is a Hindu country, and its Hindu culture and traditions must be protected from the ‘other’. Fascist violence, through state mechanisms and by Hindutva supporters, follows historical fault lines of gender, caste, and religion. It particularly targets (but is in no way limited to) Muslims. For more, refer to Banaji (2018); Desai (2008); Mehta (2017); van der Veer (1994).

<sup>5</sup> It is impossible to explain the centuries of structural oppression and violence that people have endured due to the caste system in a footnote. In brief, the caste system is a “a hierarchical social structure that categorises individuals into hereditary groups based on birth. It operates through endogamy, where marriage and social interaction are restricted within one’s caste, and determines social status and access to resources” (Krishnakumar, 2024, p. 305). Despite anti-caste activism and attempts at legal protection, caste violence in the form of everyday discrimination, exclusion from education, workplaces, and public spaces, enforced segregation, and atrocities like lynchings and sexual violence remain widespread. For more, see Ambedkar (1936); Omvedt (1994); Teltumbde (2010).

## **1.2 Writing against: the origin story of psychosocial disability**<sup>6</sup>

Are people labelled mentally ill also persons with a psychosocial disability? Do users and survivors of psychiatry identify with ‘having a psychosocial disability’? Is psychosocial disability a condition, like mental illness, and will it lead to labelling of another sort?

(Davar, 2013, p. 355)

Bhargavi Davar<sup>7</sup>, a prominent activist and academic within psychosocial disability activism in India, asked these questions more than a decade ago. While there is no consensus on what exactly psychosocial disability is, there has nevertheless been a consolidation of answers to questions such as: what does this new identity have to offer to mental health, user/survivor, and disability movements? Why might activists have taken on this identity? In other words, a singular and universal narrative of psychosocial disability and what it does has taken hold. My thesis challenges and adds to this limited narrative of psychosocial disability. This section provides the version of the singular story of psychosocial disability which I write against.

People who have experienced mental distress and/or alternate states have engaged in activism, advocacy, and research to advocate for their rights and challenge existing knowledges about them for several decades. They have been variedly known as service users, survivors of psychiatry, persons with lived experience, experts by experience, mad, consumers, persons with psychosocial disabilities, among other terms (Voronka, 2016)<sup>8</sup>. In the global North, the mobilisation of people who experience mental health ‘problems’ and/or mental health systems emerged around the collective identity of service-user and survivor of psychiatry, i.e., those who use mental health systems, and those who frame their engagement with mental health systems as traumatic and something they have survived. These terms are often shortened to ‘user’ and

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<sup>6</sup> Parts of this section were published by me in a book chapter. Full reference: Mehta, A. (2024). The radical potential of psychosocial disability activism in the global South In N. Lieketseng, M. R. Velarde, S. Singh, L. Swartz, & K. Soldatic (Eds.), *The Routledge International Handbook of Disability and Global Health* (pp. 47-59). Routledge.

<sup>7</sup> Bhargavi Davar was an activist and scholar foundational to the psychosocial disability movement in India. In 1999, she founded the organisation Bapu Trust, an influential organisation often perceived as central to the mainstream psychosocial disability movement in India. I will refer to Davar’s work and Bapu Trust throughout the thesis.

<sup>8</sup> The terms used by activists, advocates, and researchers are more than just a preference—their meanings, histories, and connotations are political, varied, complex, and specific to socio- cultural contexts (Penney & Prescott, 2016).

‘survivor’<sup>9</sup> and the movement more broadly is known as the user/survivor movement (Beresford, 2005).

In the global South, the last two decades has seen the emergence of a new collective identity location—‘person with psychosocial disabilities’ (Davar, 2013). The emergence of psychosocial disability movements and networks is credited to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) which was the first international legal instrument to explicitly recognise persons with psychosocial disabilities as rights-bearers (Davar, 2018; UN General Assembly, 2007). The World Network of Users and Survivors of Psychiatry (WNUSP)—an explicitly political network working towards creating a global user/survivor movement—played a key role in drafting the UNCRPD. Activists and advocates with psychosocial disabilities have been organising around this identity, using a rights-based discourse, and forming South-South solidarities in the form of trans-national regional networks (Pan-African Network of People with Psychosocial Disabilities (PANUSP), 2014; Redesfera Latinoamericana de la Diversidad Psicosocial, 2018; TCIAAsia-Pacific, 2018). For many activists, psychosocial disability makes key interventions by moving us away from the ‘user’ and ‘survivor’ frameworks; moving us towards disability models; and enabling a broad use of human rights discourses.

### **1.2.1 Moving away from user/survivor**

A psychosocial disability framework is framed as a form of resistance to both the imposition of Western psychiatry as well as the dominance of the global North in global user/survivor movements (Damayanti, 2018; Davar, 2018). Both user and survivor, to an extent, are framed vis-à-vis the mental health system and emerged from contexts which were “white, north country, institution-based psychiatry, high income” (Davar, 2018, para. 2). In some parts of the global South, psychiatric systems are sparse and the question of either ‘using’ or ‘surviving’ psychiatry does not arise (Robb, 2008). Even where psychiatric institutional care is the norm, Davar (2018) argued that “the identity of ‘user and survivor’ only pitched us against the dominant medical establishments” and that there is “more to life than battling psychiatrists” (para. 3, 8). There was a desire to find an identity location and framework which was distant from psychiatry, resonated

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<sup>9</sup> Within the UK, the term ‘service-user’ or user is often used to refer to people who are engaged in efforts to reform mental health service provision. ‘Survivor of psychiatry’ or survivor is often used by individuals who experience their engagement with mental health systems as traumatic and is a more politicised term within the global North context.

with the lived experience of people in the global South, and enabled activism beyond engagement with the medical systems.

The psychiatric medico-legal system is inseparable from the history of colonialism in the global South. Psychiatry in the form of mental asylums were brought to colonised communities and peoples as a form of social control by colonial powers (Mills, 2014). Colonial legacies have embedded coercive and custodial psychiatry as the norm in several parts of the global South (Pan-African Network of People with Psychosocial Disabilities (PANUSP), 2014). Despite recent attempts to institute community-based approaches and reform practices of mental healthcare and legislation, the medico-legal regimes which govern the lives of those deemed mad as well as public imaginations of mental health in contemporary times continue to be heavily influenced by custodial colonial psychiatry dominated by large psychiatric institutions (Davar, 2015a; Mills, 2014). Furthermore, even where there has been a push for deinstitutionalisation in the postcolonial era, the imposition and proliferation of psychiatric terminology, explanations, and interventions for madness persist and contemporary global health initiatives such as the Movement for Global Mental Health (MGMH) operate as a form of medical imperialism (Cosgrove et al., 2019; Mills, 2014). Following from colonial logics, and incorporating neoliberal ideas, MGMH presents peoples and communities in the global South as underdeveloped and in need of individualised interventions from the global North (Titchkosky & Aubrecht, 2015).<sup>10</sup>

Although the terminology of user/survivor presented a challenge to psychiatry within the global North, Davar (2018) argues that within the postcolonial context, there was a need for a “subaltern narrative” based on localised contexts (para. 2). The identity of ‘person with psychosocial disabilities’ then represented a disavowal of continued identification by or in relation to colonial systems (Davar, 2018; Pan-African Network of People with Psychosocial Disabilities (PANUSP), 2014).

The increased representation of users/survivors/persons with psychosocial disabilities in global forums such as the United Nations (UN) and World Health Organisation (WHO) as well as the emergence of cross-border user/survivor/psychosocial disability networks led to discussions amongst global South activists and advocates about their priorities. The discussions on the global stage focussed on global North priorities which respond to an overbearing and intrusive psychiatric system. Rejecting the dominance of the global North, activists set themselves apart

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<sup>10</sup> For more on neoliberal logics within MGMH, refer to Cosgrove & Karter, 2018.

from their global North peers by distancing themselves from ‘user/survivor’ paradigms and moving towards a psychosocial disability identity (Davar, 2015b).

### 1.2.2 Towards disability models

A disability paradigm, as embraced by psychosocial disability activists, identifies sites of change beyond healthcare—employment, education, housing, communities, transport, political participation, and so on. It provides opportunities for those deemed mad to represent themselves within existing state and international mechanisms. It enables alliances with other disability groups within an umbrella of cross-disability activism and increases “political power” and improves “bargaining positions” (Damayanti, 2018).

Before the mobilisation of disabled activists<sup>11</sup>, the medical model was the dominant model to understand disability. Much like the biomedical model of mental health, it views disability as an aberration from normal functioning and the aim of interventions, medical in nature, is to cure and/or treat the person to bring them as close to ‘normal’ functioning as possible. Under this model, disability is seen as a deficit, located within an individual, and within the remit of medicine and allied fields. Disability activists challenged this individualised and over-medicalised response to disability (Shakespeare, 2013).

Several frameworks and models of disability have emerged from/through/with disability activism. The social model of disability which is widely used by scholars and activists globally grew out of disability activism in the 1970s in the UK. The social model of disability draws a distinction between impairment—a functional limitation located within the body—and disability—societal responses which create inaccessible and discriminatory structures and practices (Shakespeare, 2013). It places the onus of inclusion and access firmly on society and enables a focus on issues such as “barrier removal, anti-discrimination legislation, independent living and other responses to social oppressions” (Shakespeare, 2013, p. 216). Around the same time, a rights model of disability emerged in the USA which positions persons with disabilities as a minority group entitled to protection of their rights under anti-discrimination legislation (Withers et al., 2019). Both the social model of disability and rights model of disability focus on social structures which create conditions of disability and marginalisation.

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<sup>11</sup> The terminology used in disability movement is varied. ‘Disabled persons’ is preferred within social model of disability activism where the focus is on how society ‘disables’ people. It is more common in the UK. Person first terminology—‘persons with disabilities’—is prominently used in disability rights models, particularly in the USA. However, as many other activists and scholars, I use the two terms interchangeably.

Psychosocial disability activists and advocates in the global South have utilised the social model and the rights model of disability to further their goals. The timely intervention of the UNCRPD and its explicit inclusion of people with psychosocial disabilities as a disabled constituency provided activists with the momentum as well as the mechanisms to hold their national governments accountable (Davar, 2018). Psychosocial disability activists have demanded to be included in disability law, legislation, and policy provisions. The enthusiastic acceptance of the social and rights models of disability and related scholarship and activism by persons with psychosocial disabilities in the global South have opened avenues of action with great potential for social change. By conceptualising ‘mental health’ as an issue of disability, psychosocial disability activists have created grounds for demanding and securing inclusion within education, employment, legal protections, political participation, and economic development activities.

### **1.2.3 Using human rights**

Following the UNCRPD, the provision and protection of human rights became a major site of intervention for psychosocial disability organisations. Psychosocial disability organisations have mobilised to pressure their countries to ratify and implement the UNCRPD and make changes within national disability and mental health legislation, engaged in strategic litigation, attempted to effect change through national human rights councils as well as made representations on global platforms, including the United Nations Human Rights Council (Davar, 2018). They have demanded a rights-based mental healthcare system. These agendas are furthered by alliances with other disability groups engaged in similar activisms.

There is no doubt that rights-based discourses play an important role in improving the status and condition of persons with psychosocial disabilities in the global South. Current legal regimes in many contexts continue to render persons with psychosocial disabilities ‘non-persons’ through incapacity provisions in criminal and civil law. This underpins coercive psychiatric care, denies persons with psychosocial disabilities the ability to exercise a range of civil and political rights, including the right to marry, adopt, inherit property, make a will, form associations, vote, and other personal freedoms, and in some cases enables abuse (Davar, 2012). A rights model wherein persons with psychosocial disabilities are considered marginalised minorities has the potential to reform current medico-legal systems. The inclusion of psychosocial disability within the UNCRPD was an important achievement for psychosocial disability activists and enabled access to rights-based discourses to effect change.

### 1.2.4 Emergence of a global ecosystem

In the last two decades, interconnected networks of disability organisations utilising discourses of human rights and increasingly of international development have emerged to fund, support, and influence projects, legislation, and programmes on local, national, and international levels (Meekosha & Soldatic, 2011; Meyers, 2016; Soldatic & Grech, 2014). Increased attention by the World Bank and the inclusion of disability in the Sustainable Development Goals (SDGs) has deepened the relationship between disability and international development (McRuer, 2007). The connections between international development and disability have been lauded by some disability activists in the global South who see it as an opportunity to promote a model of inclusive development which allows disabled peoples to better participate in the economy.

Global mental health organisations and networks, especially the MGMH, are another important influence on mental health globally. Working closely with the WHO and other health partners, and more recently with international development agencies, MGMH is a loose network of organisations, researchers, and practitioners working towards increasing evidence-based mental health services in low-and-middle income countries (Patel et al., 2018). It has been critiqued from several perspectives—imposing Western psychiatric frameworks and operating as a form of medical imperialism; framing mental health as an economic problem; defining human rights narrowly; ignoring the UNCRPD; depoliticising mental distress arising from socio-political injustices; and erasing locally situated ways of understanding mental health (Cosgrove et al., 2019). Amongst its critics are user/survivor/psychosocial disability activists who reject the psychiatric hegemony and the universalising approach of MGMH which destroys “alternative ways of thinking, being and doing, and creating ‘monocultures of the mind’” (Mills & Davar, 2016, p. 443). While it is not the central concern of psychosocial disability movements, the knowledges and approaches created by psychosocial disability activism present alternatives to the North-driven biomedicalism propagated by MGMH.

The term psychosocial disability is increasingly adopted or co-opted by academics, service providers, funders, and organisations related to human rights, disability, international development, the MGMH, and even appears in statements from the World Psychiatric Association. While usage stemming from engagement and agreement with psychosocial disability frameworks is to be celebrated, the term is also used interchangeably with or in conjunction with mental illness, mental disorders, or specific diagnoses, delinked from any disability framework. A decade ago, Davar (2013) warned us that “substituting the notion of mental illness with psychosocial disability...will once again result in mirroring the errors from the past” (p. 356). It



is this warning which creates an urgency to describe, define, analyse, and theorise psychosocial disability frameworks and praxis.

### **1.3 Writing from: psychosocial disability margins in India**

Critiques of and alternatives to the medicalisation of distress and alternate experiences are found in many scholarly and activist traditions. It would be beyond the scope of this thesis, or any one thesis, to give a full accounting of the centuries of knowledge production about and resistance to the maddening effects of structural injustice, the imposition of a universal and medicalised narrative, and the violent practices of psychiatry. This thesis is primarily concerned with unpacking and expanding beyond the dominant origin story and singular narrative of psychosocial disability presented in the section above. It starts with critiques of its foundational elements—a complete and wholesale rejection of psychiatry, the reification of the social model of disability, and the uncritical acceptance of UN-defined human rights. I write from marginal positions *within* psychosocial disability in India which expose the gaps and harms of a singular narrative of psychosocial disability but equally provide alternate stories (in the plural) of the concept.

#### **1.3.1 Outside the origin story**

The origin story of psychosocial disability, tied to the UNCRPD and the social model of disability, erases key issues within these institutions and models. Some critiques emerge from critical disability theorists as well as those engaged in justice-based activism of all sorts who question the ability of legal reform and human rights to transform society (Meekosha & Soldatic, 2011). The rights enshrined in the UNCRPD and other international human rights instruments position the nation-state as a benevolent protector (Puar, 2017). Jasbir Puar (2017) argues that this aspect of disability rights models obscures the effects of colonialism, occupation, neoliberal globalisation, and other means of oppression in the creation of disability. Further, this framing erases differences within nation-states. It does not acknowledge that access to human rights is not evenly distributed, and for some groups and communities are not accessible at all. The importance given to the UNCRPD and legal reform in framing psychosocial disability activism runs the risk of erasing those who are marginalised by the law for non-disability socio-political locations (such as class, caste, and religion, amongst others) (Meekosha & Soldatic, 2011).

Similarly, the social and rights models of disability underpinning psychosocial disability activism have been critiqued for ignoring the influence of patriarchy, white supremacy, capitalism, colonialism and neo-colonialism, and heterogeneity within the disability community, on disability

(Withers et al., 2019). Scholars highlight the need for contextualising disability to the social, political, historical, and cultural specificities of a region or community. Some warn against the dangers of homogenising the disabled and neglecting the priorities of those who face multiple social and economic marginalisations (Ghai, 2002). Moreover, the structures which create conditions of exclusion and injustice in broader society exist within disability activism (including psychosocial disability).

An intersectional approach, such as the one I and my interlocutors embrace, enables us to build psychosocial disability activism which address these interlinked marginalising structures, and centre the priorities of those who live at its intersections. Through the work of those who live and work within a wide range of transformative movements such as environmental justice, indigenous organising, anti-capitalist struggles, feminist and queer activism, movements against militarisation and occupation as well as psychosocial disability, I undertake this thesis to build and amplify understandings and practices of psychosocial disability outside the singular origin story presented above.

### **1.3.2 Making the case for India**

At various points in this thesis—when I wrote the proposal, at the upgrade, and at other times—I have been asked the question: why India? A part of me takes umbrage with this question; rarely is it asked of academics who choose to look at the USA or the UK. Much of the scholarship on activism and disability is produced in the global North and is rooted in Anglo-centric and Euro-centric traditions (Fadaee, 2017; Meekosha, 2011). Even when there is empirical research in the South, it is still tied to Euro-centric paradigms, i.e., it either understands the South through the lens of theory developed from and for the North or treats the South as a specific case to advance or challenge Northern debates (Fadaee, 2017). My analysis of psychosocial disability activism in India certainly contributes to literatures from other locations, but it is categorically not a case study. In and of itself, psychosocial disability in India is interesting and valuable.

I chose India for personal, political, and academic reasons. Within the global South, India is an important site for the development of psychosocial disability activism and movements (Mills & Davar, 2016). India is a significant focus of international development, global health, and many other transnational forces and as such is an interesting location to study their influences. In what is increasingly a rarity globally, in India, psychosocial disability activism is still dynamic and being shaped by a multiplicity of perspectives. They are messy and sometimes contradictory but equally generative where we can create multiple understandings of psychosocial disability.

I also chose India because, as is often the case but goes unacknowledged, I simply wanted to. At the outset, I was not entirely certain why I wanted to, but I believe it is instructive to unpack my motivations. It tells us something about the methodological implications of who I am as a researcher. I am and am not part of the movement in India. My experiences of madness and mental health systems (and queerness) and the ways I understood them are all based in India. However, I have for several years lived and continue to live in the UK. This dissonance is something I live with on a daily basis, as do millions of others. It crops up in my relationships, in what clothes I choose to wear, what I eat, what language I speak. With the fraught North/South relationships in the psychosocial disability movement, I belong to both and to neither. I have been told by some that I have no right to speak for/of, and definitely not *from*, India and the global South more generally. This excommunication is a deep wound, and it is partly to figure out how to navigate the partial truths in that excommunication that I decided to research India. In the same way that I picked ‘psychosocial disability’ in this thesis, and my broader work, because I sought to make sense of my mad and disabled life and to find my people, I chose India because it is both what I am close to and what I desire to be closer to.

### **1.3.3 “But who in India?”**

“Are you interested in a particular intersection? Are you focussing on a particular region?” Whenever I have told someone I am looking at India, these important questions almost always follow. And understandably so; India is a big country. However, psychosocial disability activism led by people with psychosocial disabilities are remarkably small. They constitute a handful of organisations and collectives and probably fewer than a hundred people. They are sometimes connected to mental health activism, disability movements, and lived experience-focussed settings but are distinct from them because they are generating new frameworks of mental health rather than using or reforming existing ones. Their role in the generation of new knowledge and giving voice to new frameworks endows them with remarkable power and influence, despite their limited numbers.

I made several attempts at mapping out the psychosocial disability movement I am referring to but invariably they turned out to be too messy and convoluted to make much sense (refer to Appendix A for one such example). What I call ‘mainstream psychosocial disability activism/movement’ are a small collection of organisations, closely related to each other, and to international NGOs and funders. They are largely English speaking and based in urban areas. This mainstream espouses the singular story of psychosocial disability outlined in the section above. It has some historical and contemporary links to parts of women’s movements and

increasingly queer movements but is largely disengaged from movements which address militarisation, fascism, religious persecution<sup>12</sup>, Brahminical supremacy<sup>13</sup>, Dalit Bahujan Adivasi (DBA) concerns<sup>14</sup>, and other political issues. As Hindu nationalists increasingly consolidate their power, escalate their use of violent tactics, and repress dissent and resistance, the mainstream's neglect of these critical intersections has significant implications for the psychosocial disability movement and those within it.

My thesis addresses psychosocial disability activism at the margins of, or even outside of, this mainstream movement, i.e., activism which addresses aspects of psychosocial disability neglected, ignored, and erased by it. Some of the people I interviewed locate themselves within DBA movements, queer movements, anti-fascist and anti-militarisation movements, amongst others. Their relationship to mainstream psychosocial disability is characterised by sporadic, strategic, or no engagement. Others I interviewed are more involved with the mainstream but find that their intersectional lens and connections to other movements and activism make this relationship tense and difficult. They work within small NGOs, collectives, peer groups, larger NGOs, and universities. They organise events and protests, write and create art, undertake research, do community level politicisation campaigns, are part of political education efforts, advocate for including disability issues within non-disability organisations, consult with institutions and governments, amongst many other activities. Without exception, they are all engaged in understanding and 'doing' psychosocial disability in ways that are outside the

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<sup>12</sup> Religion is a significant axis of marginalisation and shapes the social and political landscape in India. Since the electoral victory of the BJP in 2014 and the increasing influence of the Hindutva project, violence against religious minorities, particularly Muslims, has escalated. For Muslim communities, this includes economic boycotts, everyday aggression and discrimination, forced segregation, mob lynching, targeted pogroms, and widespread hate speech within pop culture and political speech. Politicians routinely call for targeted violence against Muslims and Christians. The Indian state has passed laws which particularly target religious minorities (and some DBA communities), such as the criminalising beef, religious conversions, and inter-faith marriages.

<sup>13</sup> Caste based oppression relies on the reification of dominant caste, particularly Brahmins, i.e., the most 'powerful' caste within the caste system. Brahminical supremacy in this context refers to the broader system which upholds the caste system and its violence. It is important to note that Brahminical supremacy is not practiced by Brahmins alone, the practices of caste oppression have significant regional variation, and Brahminical supremacy can be practiced by anyone who seeks to reinforce the hierarchies of the caste system. For more on refer to Teltumbde (2010) and Da Costa (2023).

<sup>14</sup> The term DBA, short for Dalit, Bahujan, and Adivasi, is used as a way to build solidarity among the communities most affected by Brahminical supremacy. Dalit is a political identity taken up by those who were formerly known and treated as 'Untouchables' and are historically and currently marginalised under the caste system. Bahujan, a related term, refers to the broader collection of communities and people marginalised by Brahminical supremacy. Adivasi or tribal is an umbrella term used to describe India's indigenous groups who have been subject to state violence, land dispossession, and cultural and linguistic erasure for centuries. For more on this, refer to Teltumbde (2010), Nath (2024) and Kikhi, Das & Dutta (eds.) (2023).

mainstream approach of legal and epistemological incorporation of madness and mental health within the social model of disability. They, and the issues they work on, are marginalised in broader society as well as within the mainstream psychosocial disability movement.

Much like how and why I chose India, I chose these marginal parts of the movement as my focus for epistemological and personal reasons. Epistemologically, these margins and the people who populate them generate critiques of mainstream psychosocial disability as well as new conceptualisations of and knowledges about the concept of psychosocial disability. Personally, they are addressing the frustrations that I have felt with the mainstream movement. Much like why I chose India, I chose them to find and be closer to ‘my people’, i.e., people I feel a certain type of kinship with.

#### **1.4 Structure of the thesis**

This thesis is essentially concerned with how activists at the margins of the psychosocial disability movement in India understand and ‘do’ psychosocial disability. Towards this end, I employed in-depth interviews with psychosocial disability activists who utilise an intersectional lens in their work. I ask and answer four main questions: first, how is psychosocial disability understood and constituted by psychosocial disability activists in India? Second, how is psychosocial disability mobilised and ‘done’ and for what purposes within the context of institutional structures and the discourses that are foundational to it? Third, how it is ‘done’ within the psychosocial disability movement? And finally, what possibilities, futures, and pathways lie within psychosocial disability activism at the margins and how are they understood and ‘done’ by those who occupy these margins?

The thesis unfolds in eight chapters, including this introduction. The next two chapters provide a review of the literature relevant to my thesis, the theoretical principles which guide it, and the methodologies which it employed. The research questions are addressed in turn in the following four chapters (Chapters Four through Chapter Seven) which report on my findings. The final chapter ties the themes from preceding chapters together and concludes the thesis.

Chapter Two locates my enquiry within existing scholarship and expands upon the theoretical principles which guide it. I start this chapter by reviewing literature concerned with Southern disability theorising, psychosocial and cross-disability activism in India, and finally, survivor scholarship on psychosocial disability. I highlight that these bodies of work do not converse with each other and uncovering the generative potential of intersectional psychosocial disability in the global South requires engagement with all of them. I then discuss the three theoretical principles

which shape my thesis—mad people as epistemic actors; activism as a site of knowledge generation; and disability as an intersectional and structural issue. I borrow from feminist, postcolonial, and crip theory to expand on these principles.

In Chapter Three, I connect the theoretical principles to my methodology. I root these discussions in an understanding of disability as method, i.e., disability as a way to do research, and a rejection of linearity, i.e., mess as generative. I then discuss how these principles shaped the decisions I made about who to interview, how to interview them, how to analyse the interviews, and the host of everyday decisions which accompany research. This chapter goes beyond describing my methodology and argues for the needs to disrupt the ableist<sup>15</sup> status quo of research methodology and provides an example of my attempt to do so.

Between Chapter Three and Four, I have inserted a map of my primary findings as well as the concepts I have used to build my analysis.

In Chapter Four, the first empirical chapter, I unpack how psychosocial disability is understood and constituted by my interlocutors. Here, I argue that psychosocial disability is collectively formed and re-formed by my interlocutors through disidentification with psychiatric frameworks as well as with conventional disability models. It is a dynamic and shifting term understood through a constant negotiation with intersecting identities, structural violence, personal meaning-making, pragmatic and strategic necessities, and embodied experiences. Beyond using it as a collective identity and a bounded legal category, as the literature would suggest, my interlocutors reformulate psychosocial disability as a lens through which they unpack and challenge multiple systems and structures of injustice.

Chapter Five builds on the previous chapter to understand how psychosocial disability is mobilised and ‘done’ within the realms of psychiatry and disability rights. Here, I argue that the use of psychosocial disability by the mainstream movement as a way to disengage with psychiatry and embrace disability rights is predicated on an assumption of a cishet Savarna<sup>16</sup> subject. Those who fall outside that subject location, including my interlocutors, undertake strategic

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<sup>15</sup> Ableism can be defined as “a system of assigning value to people’s bodies and minds based on societally constructed ideas of normality, productivity, desirability, intelligence, excellence, and fitness... This systemic oppression leads to people and society determining people’s value based on their culture, age, language, appearance, religion, birth or living place, “health/wellness” and/or their ability to satisfactorily re/produce, “excel” and “behave.” (Lewis, 2022, para. 1).

<sup>16</sup> Savarna refers to people who hold caste privilege and benefit from the caste system, maintaining their social and economic dominance. For more, refer to Da Costa (2023).

engagements with these structures and discourses, employing non-reformist or radical reform actions. Through their intersectional engagements, they understand both state-centred disability rights and psychiatry as violent and limited and their actions straddle their critiques of these systems and the everyday necessity to engage with them.

In Chapter Six, I critically examine how psychosocial disability is mobilised within the psychosocial disability movement itself. Here, I argue that the forces and tactics of neoliberalism and fascism work in concert to uphold a reward and punishment system which shape the current psychosocial disability movement and hinder radical intersectional disability action. I highlight that my interlocutors are often disillusioned by the disconnect between the current configurations of psychosocial disability activism/movement and what it should/could be. In its current form, it is defined by professionalisation, depoliticisation, and closed systems of power and capital which are then leveraged by individuals to further exclude politicised understandings and ways of ‘doing’ psychosocial disability.

In the last empirical chapter of the thesis, Chapter Seven, I root my analysis within queer and abolitionist traditions of utopian dreaming, radical hope, and everyday activism. I argue that my interlocutors engage in a range of collective political actions to enact their crip utopias in the here and now. For them, crip utopias are not just an end goal, but rather they are defined by a continual process of experimentation, failure, community, and collective action in the everyday.

Finally, the last chapter, Chapter Eight, concludes that for those who live and work at the intersection of multiple systems of marginalisation, psychosocial disability is understood and ‘done’ as a continual rejection of binaries, dichotomies, and universal or neat resolutions; rather, it is part of a much larger project of living and building justice. It is not inherently liberatory in any of its forms, but it the process of *doing* psychosocial disability intersectionally which unlocks its liberatory potential.

Scattered between these chapters are brief interludes: the thoughts, photos, poems, songs, and quotes which accompanied my journey. For some, I could not find the space or flow to include them in the main text. For others, they did not match the tone of the rest of the thesis. And for yet others, I chose not to include them in the main text for fear of taking away space from the words and lives of my interlocutors. Nevertheless, they are a part of me, and by extension a part of this thesis, and I wanted to include them somewhere.

*Interlude – on collective knowledge generation and citation practices*

*We build on the work of those who came before us, directly and indirectly. Citation is, as Sara Ahmed (2017) puts it, “how we acknowledge our debt to those who came before; those who helped us find our way when the way was obscured because we deviated from the paths we were told to follow” (p. 15).*

*We know that the work of marginalised scholars, particularly Black queer women as well as those in the global South, is less likely to be cited and thus more likely to be erased.*

*Citation practice is inherently intermingled with the oppressive structures of white supremacy, colonialism, and cisheteropatriarchy because research and academia are subject to these structures. Citation is political practice and must follow from and be congruent with the political values of this project.*

*But what of people and platforms whose actions and beliefs are in direct contradiction with and work against the justice principles I want to centre? What do I do about the people who are influential and have shaped my field but have also leveraged their power to bully and push forward hateful agendas? What do I do about platforms and journals that have long been at the centre of a discipline but in the last few years have taken transphobic stances? Do I cite the journal, lending more credence to it? Or do I refuse to cite the journal, thereby erasing the work of scholars who published in the journal years before it adopted its hateful politics? What about star professors who have been exposed as harassers or are known to take credit for the work of junior academics and research assistants?*

*There is always the option to not cite such people at all. I cannot pretend that everyone I do cite is somehow beyond reproach in their politics and behaviour, but once I know of their abusive and unethical behaviour, I cannot in good conscience cite them extensively. Katherine McKittrick (2021) asked “Do we unlearn whom we do not cite?” (p. 33). Is it not better then to cite them and within the text engage with the problems presented by the behaviour of such people and platforms. Talking to a friend about these troubles, they said that they prefer not to expend too much energy in choosing who not to cite but rather make active efforts to cite those they know are usually overlooked. I have come to no coherent position. Some people and platforms I did not cite at all, some I cited minimally and used the main text and footnotes to highlight their issues, and with others I cited alternative scholars and platforms.*



*There are other influences I found hard to include. A lot of this project is made possible only through webs of disabled friends and comrades. For me, these webs, these care webs, are also spaces of knowledge building. Disability justice, as a framework and an ethos, lives in the realm of thinking, talking, and knowledge making, but it also lives in concrete tools, accessibility hacks, and learning to care for each other. It is this latter part, intertwined with knowledge production, that I found the most difficult to cite.*

## **II. Towards a multiplicity of psychosocial disability activism(s): literature review and theoretical principles**

What would our corpus of knowledge look like if it centred the knowledges of mad people, especially those most marginalised by the oppressive structures based on caste, gender, sexuality, religious nationalism, class, and geopolitical location? At the time of its emergence, the concept and identity of ‘psychosocial disability’ was hailed as a way to undertake this task. It had sought to de-centre the global North, draw on critical disability concepts and knowledges, and establish a “subaltern narrative” situated in localised contexts (Davar, 2018). In this thesis, through an examination of how this concept is used, understood, and mobilised by people living and working at intersections of marginalisations in India, I argue that ‘psychosocial disability’ does not do this inherently. I argue that at the margins of mainstream psychosocial disability movements, there is a plethora of knowledges and practices which are erased, ignored, or ousted by the mainstream movement to favour a singular story of ‘psychosocial disability’. To establish the conceptual heritage of this study, and the key concepts that guide my investigation, this chapter first reviews relevant literatures, followed by an explication of the theoretical principles which provide the foundation for my enquiry, and finally, unpacks the different elements of my research questions.

My analysis of the literature does not simply point out the gaps within the literature. Rather, it challenges the very framing of these fields or bodies of literature. In other words, I reflect on ways in which knowledge is constructed and curated within the bodies of literature I review. Questions about knowledge generation—whose knowledges are privileged within published accounts, where knowledges are generated, what kinds of knowledges are privileged—frame the theoretical principles which guide this literature review and my thesis more broadly. The second section of the chapter elaborates on three main theoretical principles—mad people as epistemic actors; activism as a site of knowledge generation; and disability as an intersectional structural issue. Finally, in a brief third section, I restate my research questions, presenting them within the context of the preceding sections.

### **2.1 Literature review**

Choosing the relevant bodies of literature to review was a challenging task—what literatures are relevant? How do I understand relevance? Do I, or can I, cover literature from all over the world? Should I limit myself to India? Or to the global South? What about authorship? Should I concern myself only with authors with lived experience of distress and unusual experience? What

about where it is published? If I choose to, how do I include literature outside of academic book chapters and journal articles? How do I structure the section itself—from global to local, from broad to specific, or according to discipline and topic?

The primary motivation driving my literature review choices was to ensure a focus on the literatures, concepts, and authors which my interlocutors refer to or draw upon. For instance, the inclusion of abolitionist literatures here and in the empirical chapters emerged from my interlocutors' references to authors, activists, and concepts from that corpus. While there is no doubt that my analysis is sometimes driven by political and theoretical commitments different from those of my interlocutors, it is always rooted in their political, conceptual, and ethical framings.

Beyond the reasons above, two further questions guided my choice of which bodies of literature to focus on—one, where is psychosocial disability found; and two, where would we expect it to be found? The first question was easier to answer—there is a body of literature about psychosocial disability, primarily written by users, survivors, and persons with psychosocial disability. The second question gave me pause but given the emphasis on disability frameworks within psychosocial disability, I looked towards disability studies to find psychosocial disability and part of the literature review will consider this body of literature. The broader epistemological position of the thesis—that knowledges are situated, and that we must start with the knowledges of those most marginalised—provided me with clarity about questions of location and positionality from which knowledge was generated. Despite the widespread use of the term 'psychosocial disability' as a synonym for mental illness within global mental health, development studies, and psychiatric research, I am not interested in how psychosocial disability is used by *any and all* actors. I am specifically interested in how it is used and understood by those with lived experience of mental distress and alternate states. Hence, I focus on the literature generated by users, survivors of psychiatry, and persons with psychosocial disability about psychosocial disability. Sites of academic documentation would be insufficient to capture their voices; they exclude the very persons I needed to centre, especially those located in the global South<sup>17</sup>. As such, I weave through this literature review what is commonly referred to as 'grey literature', i.e., blogs, reports, news articles, and other non-peer reviewed articles as not just a way to access

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<sup>17</sup> This exclusion is inextricably linked to positioning based on geopolitical location, traditions of knowledge production, race and class, and language.

these marginalised knowledges but also to challenge the parameters which bound what is treated as knowledge (Matos & Woods, 2022).

In order to trace the lineage and trajectory of the literatures generated in the Indian context, I chose to put such literatures in conversation with broader global debates. This section thus begins with a critical discussion of the key turns in global scholarship concerned with the meaning of disability. Two key insights emerge from this sub-section—a call for, and a lack of, empirical literature on disability activism and knowledge from the global South; and with a few exceptions, a paucity of conceptualisations of psychosocial disability. The rest of this section turns towards literatures that have the potential to address these concerns. In the second sub-section, I turn to empirical writing on disability activism in India, where once again I find psychosocial disability missing. I follow this with a sub-section where I critically examine the limited writings on psychosocial disability within the Indian context. In the final section, I zoom out again to global survivor literature on psychosocial disability. These last two sub-sections find psychosocial disability but lack a critical engagement with the concept outside of legal reform and/or single-issue activism.

This literature review reveals a lacuna which my project fills. On one hand, there is a limited focus on psychosocial disability and/or the global South within mainstream disability literature. Conversely, psychosocial disability literature in the global South does not engage with intersectionality and crip theory. Furthermore, the literature that does deal with psychosocial disability in the global South presents it largely within the context of user/survivor movements in the global North and/or related to legal reform. Beyond the gaps and silences, the siloed framing of the four bodies of literature I review create and reinforce a singular story of psychosocial disability, at the expense of other ways of understanding and ‘doing’ psychosocial disability.

### **2.1.1 Disability studies, critical disability studies, and crip theory**

A critical intervention of the concept of psychosocial disability is that it aims to move mental (ill)health and madness from the medical realm and towards a disability sphere (Davar, 2015b). It is thus necessary for me to interrogate the discussions and debates within disability spheres. My thesis, as well as the work of my interlocutors, is informed by the work of critical disability studies, crip theory, and postcolonial disability scholars. To understand the arguments behind the approaches I take, we need to examine the frameworks that this work is responding to and critiquing.

I start with an explanation of disability studies as a discrete field, highlighting the emergence of the models approach to disability. I then review the arguments against disability studies made by critical disability studies and crip theory. I particularly focus on conceptualisation of disability and madness within abolitionist scholarship. Finally, I focus on the contributions of postcolonial disability scholars and the ways in which they augment/trouble global North understandings of disability. Throughout this thesis, I will return to the tensions and debates examined in this section—the separation of bodyminds and social structures; disability as a bounded category; and the neglect of theory from the global South.

### *Disability studies and the models approach*

In the 1970s, the emergence of disability rights and the social model of disability through disability activism heralded a change in how disability was conceptualised in scholarship. What was previously within the remit of medical, health, and rehabilitation sciences was now a matter for disciplines and fields such as architecture, social policy, economics, gender studies, sociology, and human rights. Disability studies emerged as a discipline with its own “discrete body of knowledge” (Meekosha & Shuttleworth, 2017, p. 49) and has:

re-sited disability as an object through which to understand the workings of capitalist society, a political category around which to mobilise, a rich phenomenon produced through social and cultural practices, an identity around which to politically organise, a cultural script marked by processes of normalisation and an ontological experience ever shaped by a host of external factors (Goodley et al., 2019, p. 974).

Disability studies, and related activism, is centred around a models approach to disability wherein different models of disability highlight different facets of disability. The medical model locates disability within an individual person and frames it as a problem requiring medical intervention. In opposition to this medicalised and individualised framing emerged the social model of disability which draws a distinction between impairment, i.e., a functional limitation located within the body; and disability, i.e., the societal responses which create inaccessible and discriminatory structures and practices (Shakespeare, 2013). This focussed research and activism on the barriers to participation which, for adherents of this model, create disability. A similar approach is the rights model of disability which also demands social change, but frames disabled people as a minority group entitled to legal protection (Withers et al., 2019). Some researchers from/in the global South have elaborated on religious or moral models of disability, which understand disability as punishment either for deeds in past lives or from a higher power as a test or curse (Bhambani, 2018). To a lesser extent some religious traditions might see disability as a

blessing from God. Finally, there is a charity model, wherein disabled people are objects of pity, to be helped and supported but not given any agency over their life. Shilpaa Anand (2016) critiques the models approach to disability, which either implicitly or explicitly, creates a linear understanding of society's approach to disability: the moral/religious and charity models gave way to the medical model, which has now been corrected by the social model and the rights model of disability.

The demedicalisation of disability through the establishment of disability studies and the mobilisation of the social and rights models of disability has critical implications for disability activism. First, by creating a distinction between impairment and disability, it constructed a disability category and identity which encompassed different impairment groups. Second, it shifted the focus of action and activism entirely towards social inequalities to the detriment of any discussion of embodied experiences of impairment and disability. For people deemed mad or mentally ill, the move away from medicalisation and the body as well as inclusion within a disability identity is central to the concept of psychosocial disability. My thesis explores the pathways of action made possible by this approach to psychosocial disability, but equally its limitations.

#### *Critical disability studies and crip theory: challenging binaries*

The re-evaluation of existing explanatory models of disability, especially the prominent social model of disability, gained traction in the early 2000s (Meekosha & Shuttleworth, 2017). The emerging fields and theories termed 'critical disability studies', disability critical race theory (DisCrit), and crip theory acknowledged the utility of the social model of disability as a tool for political activism but also sought to address its shortcomings—neglect of the body, co-option, lack of intersectionality, limited understandings of who counts as disabled (Annamma et al., 2018; Kafer, 2013).

Critical disability studies (CDS) scholars argue that the social model of disability's (and disability studies more broadly) neglect of the entanglement of body and society hinders analyses of the diverse ways disability is experienced (Shakespeare, 2013). Feminist, cultural studies, and postmodernist and poststructuralist rejection of binaries (impairment vs disability; medical vs social model) influenced the emergence of CDS. The rise of postmodern leanings in cultural studies and humanities shifted the modes of engagement with disability and social justice to incorporate the discursive, cultural, psychological, and carnal into the social and economic (Meekosha & Shuttleworth, 2017). Although traditional disability studies was successful in distancing itself from a medicalised view of disability, in the last two decades medical and

rehabilitative institutions and disciplines have co-opted the term ‘disability studies’ as evidenced by their abundant use of the term but without the necessary critiques of the medical model. Critical disability scholars have hastened to distance themselves from co-opted terminology<sup>18</sup> (Meekosha & Shuttleworth, 2017; Tew, 2015).

The rise of disciplines such as critical race theory, critical queer studies, and critical legal theory have provided “theoretical, conceptual and methodological examples” for disability scholars (Meekosha & Shuttleworth, 2017, p. 51). An explicit focus on intersectionality and engagement with Black feminist scholarship and critical race theory within CDS and the emergence of frameworks such as disability critical race theory (DisCrit) and crip-of-colour are beginning to address mainstream disability studies’ failure to “engage issues of race and ethnicity in a substantive capacity, thereby entrenching whiteness as its constitutive underpinning” (Annamma et al., 2018; Bell, 2006, p. 275; Kim, 2017). CDS aims to incorporate theory and concepts from diverse disciplines, and include perspectives and knowledges which traditional disability studies excluded. Goodley et al. (2019) describe critical disability studies as a:

location populated by people who advocate building upon the foundational perspectives of disability studies while integrating new and transformative agendas associated with postcolonial, queer, and feminist theories (p. 974).

At the intersection of queer studies and critical disability studies, scholar-activists have developed crip theory, using the word ‘crip’ as a reclamation of the derogatory word ‘cripple’. Crip theory aims to disrupt the binary categories of disabled and non-disabled and unpack how these categories come to be constructed (Kafer, 2013). Carrie Sandahl (2003) emphasises the fluidity of the term crip and its ability to “include not only those with physical impairments but those with sensory or mental impairments as well” (p. 27). Alison Kafer (2013) points out that crip or crip affiliation includes:

those who lack a 'proper' (read: medically acceptable, doctor-provided, and insurer-approved) diagnosis for their symptoms... [and]...people identifying with disability and lacking not only a diagnosis but any 'symptoms' of impairment (p. 12-13).

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<sup>18</sup> This trajectory is not dissimilar to the idea of ‘recovery’ in survivor research which was initially conceptualised as a challenge to the medicalised view of chronic mental illness and towards holistic and emancipatory care. Over time the recovery discourse was co-opted and professionalised by neoliberal systems linking individual responsibility to recovery. This undermined the political and advocacy elements of the recovery discourse put forward by survivor activists. Survivor activists, much like critical disability scholars, have hastened to distance themselves from co-opted terminology.

In the way that the word queer has come to encompass multiple non-heteronormative subjectivities, crip enables the inclusion of all those with non-normative bodies (and minds). Crip theory in this way extends beyond the remit of traditional disability studies by including fatness, chronic illness, neurodivergence, and madness. It is a liberatory and transformative paradigm and celebrates alternate and different ways of being in the world. Crip, like queer, can be used as a verb to disrupt "mainstream representations or practices to reveal able-bodied assumptions and exclusionary effects" (Sandahl, 2003, p. 37). This leads me to ask if/how 'psychosocial disability', as used by activists, 'crips' madness and mental (ill)health?

### *Abolitionist scholarship and disability*

An important site of critical perspectives on disability and mental health is abolitionist scholarship. Much of abolitionist scholarship is concerned with, and emerges from, activism and organising and its insights are relevant to all activism. As the empirical chapters will show, my interlocutors refer to authors, texts, and concepts embedded within it to discuss their relationship to disability activism. This sub-section, hence, works to situate those later discussions.

In short, abolitionist scholarship and activism seek to dismantle carceral systems (including but not limited to prisons), to build non-punitive systems, and to transform broader society. While the abolition of carceral systems is at the core abolitionist thinking, Ruth Wilson Gilmore reminds us that it is equally "presence" and "building life-affirming institutions" (Davis et al., 2022, p. 52). In other words, abolitionist aims go beyond simply closing prisons or defunding police; rather they include the creation of community-led non-punitive systems of accountability. For abolitionists, prisons and policing are not 'broken' but rather they are inherently unjust. As such, they critique reform efforts which seek to simply improve existing carceral systems (e.g., better prisons, more humane policing) without questioning their very existence. They draw a critical distinction between reformist reforms and non-reformist reforms. The former, extend the reach and power of the very systems they are attempting to reform, leading to an expansion of punishment (Davis, 2003). The latter are also incremental changes, but they are aimed at reducing the power and scope of carceral institutions. These non-reformist strategies are not the endpoint but a means to the larger vision of abolition (Kaba, 2021; Marbre & Akbar, 2022). I will return to this concept of non-reformist reforms in Chapter V.

Many abolitionists have long argued that prisons disproportionately incarcerate disabled and mad persons. Similar to many critical disability scholars, they point out that the violent conditions of prisons (and society more broadly) create and cause disability and mental distress. Some



abolitionists increasingly recognise that carceral logics permeate beyond prisons and include ‘care’ institutions designed to address disability and mental ill-health. Liat Ben-Moshe (2020), noting that “disability and madness are largely missing from analysis of incarceration and its resistance” (p1), goes further and argues that race and disability are co-constituted within carceral logics. She brings together abolitionist thinking and crip-of-colour critique in her analysis of deinstitutionalisation in the 1960s in the USA to argue that abolitionist aims are achievable. For her, and others like Mariame Kaba, the utopian thinking that drives abolitionist activism is about both radical re-imaginings as well as the practical everyday work of organising, creating communities, and practicing non-punitive accountability. I will come back to these themes in Chapter VII.

An abolitionist lens enables a critical re-thinking of mad and disability activism. For instance, many have pointed out that supposed alternatives to institutionalisation such as community orders, half-way homes, etc often work to strengthen or extend the carceral power of psychiatry by bringing it into the community or by replacing one oppressive system with another (Mad Liberation Front, 2021; Steele, 2020). Despite the clear alignments between survivor, abolitionist, and disability scholarship on psychiatry, these fields remain siloed with few exceptions. Further, the intersection of madness, disability, and abolition is under-explored in the context of the global South.

#### *Postcolonial disability studies: finding the global South*

A crucial critique of disability studies comes from those concerned with disability and the global South. Shaun Grech (2015) contends that disability studies has ignored the global South, while postcolonial studies has neglected an analysis of disability. The rhetoric of colonisation (disabled bodies as the site of medical colonisation) by the former and the employment of the metaphor of disability (colonialism as disabling) by the latter decontextualise the materiality of both disability and the colonial encounter (Sherry, 2007). Nirmala Erevelles and Kafer (2010) note that “disability studies scholars seem unprepared or unwilling to engage disability as being constituted within oppressive contexts of violence as the result of transnational capitalism, neocolonialism, and sexual and other violence” (p. 208). Disability and colonialism are bound together both historically and in the postcolonial context. Further, Helen Meekosha (2011) challenges the neutrality of impairment implied by the social model of disability and re-positions it as socially (and politically) produced and inscribed through exploitative enduring conditions arising from the interrelationship of colonialism and capitalism in the global South. Aligned with this scholarship, I aim to understand disability conceptualisations and mobilisations from the global

South, as constituted and created through repressive structures but also as embodied and material experiences.

Puar (2017) further troubles the Northern (white) frameworks of disability by bringing our attention to the way disability rights models obscure the effects of colonialism, occupation, neoliberal globalisation, and other means of oppression by viewing the nation-state as a benevolent rights-giver. She argues that the state is complicit in producing what she terms debility. Debility, in contrast with disability's focus on a singular causative event, captures the ways our bodies are held in a sustained state of fragility, fatigue, chronic unwellness, pain, and other forms of difference or loss of functioning. Debility is the liminal state between being able-bodied enough for neoliberalism and being recognised as disabled. In this way, Puar (2017) adds to critiques of the binary between disabled and non-disabled and furthers our analysis of who/what is served by the construction of such categorisations. Neither Puar (2017) nor Meekosha (2008) explicitly mention psychosocial disability although both the production of impairment and debility are relevant to mental distress and/or alternate and unusual experiences.

Furthermore, Anita Ghai (2002) highlights the need to locate disability within the specificities of social, political, historical, and cultural contexts. Following from Chandra Talpade Mohanty's (2008) writing on Third World women, she warns us against homogenising the disabled in India and points to the multiple social and economic marginalisations including but not limited to caste, gender, and class that frame the disabled experience. She argues that postcolonial theory provides a lens through which such diversity can be foregrounded and that there is an urgent need to theorise disability that "responds to the concerns of the Indian experience of disability" (Ghai, 2002, p. 96).

Postcolonial disability studies thus reveals an urgent need to theorise from the South, to foreground the experiences of the majority world where 80% of all disabled people live, and to examine the contexts of colonialism, neocolonialism, and globalisation as well as the local geopolitical and historical specificities. Grech (2015) helpfully reminds us to:

prioritise epistemic, experiential, cosmological and practical insights and perspectives from subaltern global South spaces, usefully aligning with the call for 'crip experiences and epistemologies' in disability studies in the bid to provide access to 'alternative ways of being' (p. 18)

It is this call which I take forward in my thesis. By foregrounding the voices and work of psychosocially disabled activists in India, this thesis unpacks how activists utilise aspects of the

different approaches to disability depending on the particularities of their context. They critically engage with the social model of disability with all its limitations and equally work towards actioning the more expansive and radical concepts offered by crip theory, abolitionist scholarship, and critical disability studies. In doing so, they not only disrupt the dichotomies offered by global North-dominated disability studies but also trouble the distinctions between these different fields and disciplines.

### **2.1.2 Cross-disability activism in India**

Psychosocial disability positions madness as a part of an umbrella category comprising different disability and impairment groups. It is, hence, important to understand cross-disability activism in India, i.e., activism that is not restricted to a specific impairment/disability type; rather that which encompasses and is inclusive of several disability categories (Bhambani, 2018). What parts of disability theory have translated into activist action and what has been ignored? What does disability as a unifying identity and concept look like in practice, especially for those who might not fit into it neatly, i.e., persons with psychosocial disabilities? Disability and disability activism, as argued above, are always situated. While there are resonances across different regions, countries, and contexts, it is helpful to embed this section within India to better understand the dilemmas my interlocutors face and the choices they make. Therefore, in this sub-section, I review empirical literature on disability organising in India and the external and internal influences which shape and define it. I set out linkages to my work, and then consider how psychosocial disability may fit, problematise, and/or extend understandings of cross-disability activism in India. In my thesis, I fill the gaps in this literature by incorporating an intersectional lens to examine the oft-neglected activism of persons with psychosocial disabilities within the context of cross-disability movements.

A full telling of all the organising by different impairment/disability constituencies in India is neither feasible, nor entirely relevant to my thesis. In brief, the origin story of disability movements in India is contested but it is largely accepted that in the late 1970s, disability activists began vocalising the concerns of disabled persons. For some, the National Federation of the Blind<sup>19</sup> founded in 1970 marks the establishment of disability organising in India (Chander, 2018). However, others point out that this organising was largely restricted to those with visual impairments and hence does not constitute cross-disability activism. For them, international influences such as the declaration of the International Year of the Disabled Persons by the

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<sup>19</sup> Initially called the National Federation of the Blind Graduates

United Nations in 1981, the launch of the Asian and Pacific Decade of Disabled Persons in 1993, and disability movements in other parts of the world were the impetus for disability organising and legislative reform in India (Bhambani, 2018; Ghai, 2003; Mehrotra, 2011). The concept of ‘disability’ itself rather than different impairments travelled from disability studies, the models approach to disability, as well as global disability activism. Nilika Mehrotra (2011) argues that disability legislative reform in India was a result of international pressure and the rise of other social justice movements in the country. However it came to be, there is a diverse and varied range of cross-disability organising in India in contemporary times. The key concerns of the literature related to it and relevant to me are twofold: one, where and what types of disability organising is taking place; and second, the tensions and contestations within the cross-disability umbrella category.

Cross-disability organisations utilise rights-based discourses (in their varied articulations); focus on development activities and community projects; mobilise to reform disability legislation; include awareness raising activities; and generate scholarship. This broad and diverse focus is not exclusive to cross-disability movement; it finds resonance in many social movements including the women’s movement and queer movements and as this thesis argues, within psychosocial disability activism (Althen, 2011; Govinda, 2006).

Mehrotra (2011) makes distinctions between different cross-disability organisations, highlighting the importance of their specific focus, strategies, location, and structures. First, they identify individual-centred organisations led by urban elites focussed on advocacy, legislation reform, and making demands on the state using rights-based discourses. They use lawsuits, formal complaints, and web-based disability mobilisation to achieve their aims. These organisations and their strategies mirrors what I call the mainstream psychosocial disability movement/activism in my thesis. Second, Mehrotra (2011) positions academic scholarship which utilises disability research and theory as a part of cross-disability activism. A critique of both these sites of cross-disability activism is their lack of connection to grassroots social justice movements and with the exception of gender, their neglect of intersections (such as caste and religion) which mediate disability, a criticism which I and my interlocutors share in regard to mainstream psychosocial disability.

Third, Mehrotra (2011) identifies non-governmental organisations (NGOs) working with the rural and urban poor, focussed on community-based rehabilitation, and closely linked to the development agenda. However, bigger NGOs which have extensive international connections, often drive the structures and priorities of grassroots Disabled Persons Organisations (DPOs) or

Self-Help Groups (SHGs) (Ghosh, 2016). Nandini Ghosh (2016), in her analysis of such grassroots organisations across India, notes several factors influencing their trajectories. Local history and culture of people's movements as well as the age of the group affect the strategies and political stances of the DPOs. Additionally, the local government policy plays an important role in shaping the primary activity of the group. For instance, a government policy extending benefits to self-help groups (SHGs) creates incentives for DPOs to re-brand themselves as SHGs. These observations highlight the importance of situatedness in disability activism. In a social and political context as diverse as India, psychosocial disability activism will inextricably be linked to the local specificities of their context.

The three types of disability organising identified by Mehrotra (2011) and others are presented as distinct from each other and operating in different disconnected spheres. Tanmoy Bhattacharya (2018) claims, disability activism is “estranged” from disability scholarship in India. Ghosh (2016) finds that the grassroots NGOs use the language of human rights found in the urban elite organisations but interpret them as “entitlements and schemes” to help with income generation and livelihood (p. 191). While that may also be the case for psychosocial disability, part of my argument is that by centring those who live and work in intersectional and liminal spheres, we might more clearly see the connections and interrelationships between them.

Despite this seemingly flourishing cross-disability action, in India, some scholars have interrogated its underlying assumption—cross-disability as a coherent category. They argue that cross-disability as a concept is built on tenuous alliances between disability groups and is at odds with disability legislation which remains tied to impairment-specific benefits<sup>20</sup> (Friedner et al., 2018). By focussing on commonalities between disability categories, a cross-disability umbrella can obscure the differences in the ways different disabilities are experienced. Analyses of queer movements reveal similar tensions—queer functions as an umbrella which has the potential to build solidarities but equally can neglect the concerns of certain queer groups (Radhakrishnan, 2019). In contrast to ‘queer’ as an umbrella which scholars have argued has a basis in the Indian historical context, Friedner et al. (2018) contend that cross-disability is a “techno-moral” concept

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<sup>20</sup> The first disability legislation in India—Persons with Disabilities (Equal Rights and Full Participation) Act 1995 (PWD 1995)—used impairment categories (including an undefined category for mental illness) and a level of impairment assessment as a basis for eligibility for positive discrimination. Following the ratification of the UNCRPD in 2007, the consultation process for what would become the Rights of Persons with Disability (RPD) Act began in 2009. A diverse group of activists, experts, and disabled persons groups were initially involved (including mental disability) in the drafting process. However, the final version of the Act, passed in 2017, was critiqued by disability activists for ignoring their recommendations and its close ties to impairment categories and the medical model.

providing a unifying meta-narrative based on human rights discourses and rooted in urban centres linked to international and state funding (Vanita & Kidwai, 2008).

Arguing that any disability category “has a constitutive outside”, Friedner et al. (2018) trouble the cross-disability category by asking “Who is included and on what grounds? What kinds of compromises by disability activists are required to create ‘cross-disability’ inclusion?” (para. 6). They highlight these tensions by using two examples from the cross-disability stakeholder consultation process for the Rights of Persons with Disabilities (RPD) Act 2016. First, historical trajectories of impairment-specific activism and welfare benefit categories have led to ‘dominant disability categories’ (visual, hearing, and locomotor disabilities). These power imbalances within the cross-disability category provide a challenge to broadening the definition of disability, for instance to include chronic illnesses.

Second, the influence of UNCRPD necessitated a debate on legal capacity<sup>21</sup>. On one hand, parents/carers of intellectually disabled persons, anxious about the lack of support mechanisms to exercise legal capacity, argued against it. On the other hand, persons living with mental illness, as the authors call them, argued for it (Friedner et al., 2018). Legal capacity is an important issue for psychosocial disability activists. It, however, exposes several schisms which will re-appear in later chapters of this thesis: between user/survivor and carer groups; between those who seek to abolish the psychiatric system and those who seek to make the system less traumatic; between the global North (mainly concerned with involuntary treatment) and the global South (also concerned with civil and political rights).

Both these examples highlight the difficulties of sustaining a cross-disability alliance where differences between and within disability constituencies require different approaches to meet demands. They expose the complex ways in which “different disability categories are negotiated” and how “state structures create conditions of (im)possibility for disability categories to be rendered commensurable and/or for diverse disabled people to come together” (Friedner et al., 2018, para. 8). The authors above call for a complex and nuanced study of disability movements which pays attention to the local socio-political contexts as well as international influences.

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<sup>21</sup> The right to legal capacity enshrined within the UNCRPD Article 12 (equal recognition before law) states that no person can be denied the right to make their own legal decisions on the basis of disability. Current regimes of involuntary treatment (as well as the exclusion of persons with psychosocial disability from exercising their civil and political rights) are based on the medico-legal understanding that persons deemed mad do not have the ‘capacity’ to make informed decisions.

I build on the questions and tensions unearthed by Friedner et al (2018) and ask what ‘psychosocial disability’ does for psychosocial disability activists, cross-disability movements, for international actors, and for the Indian state? Who or what experiences and knowledges are excluded from our understanding of psychosocial disability? In what ways do the cross-disability tensions and alliances in India shape/disrupt/change psychosocial disability activism? Questions such as these enable me to unpack the structures and power entanglements which shape and define psychosocial disability activism.

### **2.1.3 Psychosocial disability in the Indian context**

Most directly relevant to my thesis is a small body of emerging literature on psychosocial disability in India from the perspective of persons with psychosocial disabilities. However, much of it stems from the work of one organisation (Bapu Trust) led by a scholar-activist with psychosocial disabilities. Bhargavi Davar has incisively outlined various debates in the field—historicising the psychosocial disability identity within the specific local context of the women’s movement as well as colonial legacies; linking national legislation and international human rights instruments; and exploring Bapu Trust’s efforts to mobilise around a psychosocial identity and framework (Davar, 2012, 2013, 2015b, 2015c; Mills & Davar, 2016).

However, as Davar (2015c) herself warns us, “master narratives” undermine the diversity and complexity of mental health and disability activism (p. 175). Apart from gender, this emerging literature does not offer an analysis of social and political locations which intersect with disability. It centres the UNCRPD in the emergence of psychosocial disability and neglects the multiple meanings of ‘psychosocial disability’ outside legal instruments. These absences are critical gaps and risk erasing the multiplicities of psychosocial disability activism by favouring a single story about it.

#### *Why we need a psychosocial disability identity?*

Despite the emergence of psychosocial disability in activism and advocacy, there is a lack of definitional literature on it. There is an urgent need to theorise distress “in terms of psychosocial disability” instead of simply substituting it in place of ‘mental illness’ which would result in “mirroring errors from the past” (Davar, 2013, p. 356). This project partially responds to this call for a framework of psychosocial disability emerging from the work of activists. I would argue, as Davar (2013, 2015a, 2015b, 2015c) and Renu Addlakha (2015) do, that this theorisation must be grounded and rooted in social and political specificities. They have sought to clarify the potential

of psychosocial disability as an identity to challenge the interlinked systems of colonialism, patriarchy, and psychiatry.

Mental health care and legislation in India is “modelled upon colonial legal and architectural designs” (Davar, 2015b, p. 224). Despite epistemic shifts in the legal discourse (lunatic, unsound mind, mentally ill, persons with high support needs), those deemed mad continue to be treated as legal “non-persons” under 150 provisions in Indian civil and criminal law. The consequences of this legal non-personhood, originating in colonial laws and carried forward in post-Independence India, ranges from the ability to form associations, coercive treatment and deprivation of personal liberty, access to justice and family law amounting to what Davar (2015b) calls a “civil death”. Women are disproportionately affected by abuses of legal power highlighting the relationship between patriarchy and psychiatry (Davar, 2015c).

The women’s movement and feminist scholarship have challenged the oppressions at this intersection by first, theorising ‘madness as protest against patriarchy’, rejecting wholesale the idea of psychiatric illness. However, Davar (2013) reflects that this led to a rejection of the lived experience of fragility, vulnerability, and distress. A second and subsequent shift in the feminist movement’s critique of psychiatry turned to efforts to reform psychiatric/mental health systems to attend to the specificities of women’s madness without the wholesale rejection of concept of mental illness. While acknowledging distress, this turn rejected non-medical forms of healing rooted in spirituality. In retrospect Davar (2013) also points out that this approach reinforced the medical model of mental health and “ended up creating a market for the psychiatric/psychopharmaceutical industry” (Davar, 2013, p. 351). This is what Davar (2013) refers to as the “errors from the past” where critical challenges to psychiatry failed to centre lived experience on one hand and to decentre psychiatry on the other.

Davar (2015b) contends that a psychosocial disability identity can encompass both a recognition of suffering and the possibilities of healing as well distance from the stigmatising labelling of psychiatry. Further, it has the potential to transform colonial legislation and systems in favour of a human rights framework. The UNCRPD has provided a normative framework for psychosocial disability. It was created within the context of an emerging trans-national resistance to the medicalisation of mental health in the form of a global user/survivor movement.

Anchoring her discussion in the intense debates on identity in a meeting—Asian Consultation of Disabled Activists—Davar (2015b) highlights how psychosocial disability has the potential to reject both the language of mental illness (which is tied to psychiatrisation) as well as user/survivor (constructed vis-à-vis mental health systems in a global North context). It can



therefore challenge the coloniality in both the Western imposition of psychiatry and within the Western resistance to psychiatry. However, there is little critical discussion on the UNCRPD itself as a Western legal instrument or the coloniality within the United Nations which is tasked with monitoring its implementation.

Despite increasing mobilisation “based on an emerging [psychosocial] disability identity”, its relationship to disability advocacy, activism, and scholarship is contested (Davar, 2015b, p. 226). Addlakha (2015) uses a feminist lens to examine case studies of two women with physical and psychosocial disability, respectively. Drawing from the convergences in their experiences, including gendered experiences of disability, she puts forth that a disability framework for chronic illness could bridge the gap between physical and psychosocial disability. Would a chronic illness framework provide sufficient distance from medicalisation which Davar (2013) claims is a key aspect of psychosocial disability? In any case, the key tenets of critical disability studies and crip theory which Addlakha (2015) draws on—rejection of binaries, intersectionality, fluidity of disability—enable a disability reading of ‘madness’. My thesis, firmly grounded within activism, takes up these tenets and examines the pathways of action which they enable and/or hinder.

#### *Is the law central to a psychosocial disability framework?*

The existing literature centres legal instruments—national legislation and the UNCRPD—in mediating a psychosocial disability identity in India. This is partially a consequence of India’s ratification of the UNCRPD in 2007 and subsequent efforts to reform national disability and mental health legislation as a key impetus for psychosocial disability activism.

First, the UNCRPD unequivocally places mental health within the realm of disability law in the form of psychosocial disability. The need for this shift is highlighted by existing mental health legislation which is the “ideational counterpoint to the disability studies approach” due to its continued reliance on coercion and substituted decision-making (Dhanda, 2018, p. 394). Despite efforts to incorporate mental health within disability legislation, tensions with other disability constituencies (particularly family and carer groups) persist (Friedner et al., 2018).

To an extent, these tensions are related to the second important intervention by the UNCRPD—Article 12 and the right to legal capacity. In contravention of Article 12 (equal recognition before law), in India the legal ‘non-personhood’ of persons with ‘unsound minds’ is rooted in a series of incapacity provisions in criminal and civil law. This enables coercive psychiatric care and denies persons with psychosocial disabilities the ability to exercise a range of

civil and political rights (Davar, 2012). Further, Davar (2012) refers to the importance of Article 19 of the UNCRPD—the right to live independently and inclusion in the community. She argues, despite mental health legislative reform, the Mental Health Care Act 2017 (MHCA) contradicts both Article 12 and Article 19 of the UNCRPD.

Underlining the importance of contextualising Article 12 of the UNCRPD within “local histories, ways of understanding, perceptions, social organisation and cultures”, Davar (2015c) notes that nuance is currently absent from global North focussed literature (p. 175). The importance of a locally situated discussion of the UNCRPD is highlighted by the clear links between legal capacity and civil and political rights.

The question of whether legal reform and human rights can truly transform society is not exclusive to India (Meekosha & Soldatic, 2011). The importance given to the UNCRPD and legal reform in framing psychosocial disability activism runs the risk of erasing those who are marginalised by the law for non-disability socio-political locations (such as class, caste, or religion). This is particularly highlighted as the current regime in India leverages the law to detain political prisoners, including those with disabilities (Vijayan & Rechia, 2023).

We can draw links between the legal focus of the psychosocial disability movement to the queer movement in India. In the last two decades, a large part of the visible queer movement was focussed on repealing a section of the Indian Penal Code (Section 377)<sup>22</sup> which, in effect, criminalised same sex sexual activity. The fight against Section 377, despite primarily affecting gay men who are a sub-section of queer communities, came to define the queer movement in the public imagination. However, in contrast to psychosocial disability, a diverse range of queer issues and perspectives are articulated within scholarship and the arts (Narain & Bhan, 2009; Vanita & Kidwai, 2008; Varghese & Mehta, 2018). I argue that a body of literature on psychosocial disability should similarly include non-legal aspects of the concept, and this project serves as a contribution to that budding field of scholarship.

### *Actioning psychosocial disability*

There is little written and publicly available documentation regarding how psychosocial disability is mobilised and/or actioned in India, with the exception of the work of Bapu Trust. An analysis

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<sup>22</sup> Section 377 of the Indian Penal Code, in the image of colonial sodomy laws, criminalised “carnal intercourse against the order of nature”, essentially criminalising same-sex sexual activity. Queer activists, sex worker collectives, and people with HIV led the decades-long activist fight against Section 377. It was struck down in 2009, re-instated in 2013, and finally repealed by the Supreme Court of India on 6 September 2018.

of a multi-stakeholder project aimed at building self-advocacy capacity describes psychosocial disability not just as an identity but as a social model of disability framework which “emphasizes that exclusion and discrimination which disable is a result of the inappropriate social response to the needs of people with ‘different’ psychological experiences” (Gombos & Dhanda, 2009, p. iv). The authors outline barriers to effective advocacy: the social and legal risks of public disclosure as a disabled person; negative social attitudes; segmented approach of existing psychosocial disability advocacy; and self-advocacy and/or disability advocacy being unpaid work. The report identifies key strategies for the future including a multi-sectoral approach with alliances within the disability sector and community-centred approaches. China Mills and Davar (2016) also call for locally situated community projects in contrast to the universalising approach of MGMH which, according to them, destroys “alternative ways of thinking, being and doing, and creating ‘monocultures of the mind’” (p. 443). They provide an example of such a programme—*Seher*, the flagship programme of Bapu Trust—which aims to create sustainable communities by focusing on strengthening social and economic community resources, peer support, rights-based mental healthcare, and integrating non-medical healing traditions within the community. In contrast to other social movements, within psychosocial disability, there is, little exploration of what constitutes a ‘community’ nor of those who are excluded from it based on caste, class, occupation, religion, etc. (Govinda, 2014; Vanita, 1999)

The existing literature on psychosocial disability does not engage meaningfully with critical disability studies or crip theory; intersectionality; and critical thinking on human rights. Although it comments on global power imbalances, it does not reflect on the power structures within India. The UNCRPD and the promise of legislative reform is a significant point of concern for this body of literature. However, human rights are not accessible to all, and a rights-based framing of psychosocial disability can obscure state complicity in creating psychosocial distress. This narrow framing of psychosocial disability is a potential consequence of the lack of diversity within the literature. This project will explicate how a materially different framework of psychosocial disability can include intersectional, inclusive, and emancipatory frameworks which might exist outside the UNCRPD.

#### **2.1.4 Global survivor literature on psychosocial disability**

Psychosocial disability as a global South concept emerged in part as a response to global North-centric user/survivor movements and frameworks. In the last decade, psychosocial disability and the debates surrounding it have been taken up by actors beyond activist realms in the global South. As I set out in the beginning of this chapter, my thesis is primarily concerned with how

people with lived experience understand and use psychosocial disability. This sub-section hence focuses on literature from user/survivor movements and scholarship which explores the potential of, and problems related to psychosocial disability as a concept. First, and in common with the first section of this literature review, the UNCRPD and legal capacity are an important theme. Second, the contradictions between how madness is understood within the global North user/survivor movement and its fit, or lack thereof, with the social model of disability is emphasised. Finally, a small minority of authors have attempted to look beyond the social model of disability and examined if other fields and disciplines, including crip and critical disability studies, can inform our understanding of psychosocial disability.

Despite burgeoning psychosocial disability activism in the global South, this body of literature does not meaningfully engage with any Southern disability scholarship. This drawback narrows the possibilities of new framings of psychosocial disability: it represents the UNCRPD only within the context of involuntary treatment (a concern of most relevance in the global North) ignoring its importance in other realms of life; it critiques the social model of disability from the perspective of madness but does not engage with postcolonial disability and crip theory which make similar critiques.

### *Legal capacity and the UNCRPD*

The UNCRPD, recognised as the galvanising force behind the emergence of the psychosocial disability framework, is the first strand of this body of literature. Article 12 (equal recognition before the law and legal capacity) is of particular concern to survivor researchers globally (Committee on the Rights of Persons with Disabilities, 2014). Legal capacity includes the “capacity to be both a holder of rights and an actor under the law” and enables persons with psychosocial disabilities to be rights-bearers (Committee on the Rights of Persons with Disabilities, 2014, p. 3). The UNCRPD thus overturns legal regimes which do now allow for people with ‘mental illnesses’ to make informed choices about their life decisions including healthcare. In the highly psychiatrised context of the global North where coerced treatment happens under legal provisions in hospitals, legal capacity is almost entirely discussed in relation to involuntary/forced treatment. The user/survivor movement in the global North does not engage with scholars such as Davar and has neglected the broader implications of legal capacity for civil and political rights (right to vote, right to marry, financial rights). Further, in the majority world, coercion is often practiced within family and community structures (and not solely in institutions) and other parts of the UNCRPD, such as Article 19 (inclusion in the community), are as relevant as legal capacity in user/survivor activism (Davar, 2018).

Within the global North, on one hand, Article 12 is lauded as a victory and a step towards the abolition of forced psychiatric treatment which, according to Tina Minkowitz (2015)<sup>23</sup>, has been a key goal of the user/survivor movement. On the other hand, the UNCRPD does not engage with the important wider and complex issues of agency; risk and safety; responsibility and morality; and expressed wish and consent (Plumb, 2015). Anne Plumb (2015) argues that these are critical issues in any discussion on external intervention for mental health crises particularly for ‘non-ordinary experiences’ (diagnosed as psychosis) and suicidality. In the absence of non-coercive alternatives, ‘choice’ and ‘informed consent’ are hollow signifiers. Further, within neoliberal contexts, the UNCRPD’s critique of mental health institutions can be used to justify removing, rather than transforming, state mental health services. In conclusion, Plumb (2015) warns that the UNCRPD “takes us out of the frying pan of psychiatry and state provision and into the fire of libertarian ideology” (p. 189).

### *Impairment, madness, and the social model of disability*

Most survivor research emerging from the UK focuses on the differences between physical disability and madness, particularly regarding impairment and uses the social model of disability as a point of departure. With few exceptions, there is little engagement with critical disability, postcolonial, and crip scholarship which have the potential to make critical interventions in these debates (Jones & Kelly, 2015). Grappling with the differences in the constructions of impairment, illness, disorder, and identity across the globe is key to building meaningful relationships between madness and disability (Jones & Kelly, 2015). A global South framework of psychosocial disability which incorporates intersectionality and accommodates diversity will have much to add to the following debates.

The social model of disability locates impairment within the body. This, survivor researchers argue, presents three main problems for the user/survivor movement. First, despite the contested nature of diagnosis and biological basis of mental illness, disability policy (using the social model of disability) relies on and further entrenches diagnostic categories by validating them as legal categories of disability (Beresford, 2000; Penson, 2015; Plumb, 2011, 2015; Rashed, 2019). This echoes the concerns of Indian activists about the enmeshment of disability legislation and medicalisation (Friedner et al., 2018). Second, Plumb (2015) argues that under the

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<sup>23</sup> Minkowitz is a human rights lawyer and survivor activist who was a key member of the UNCRPD negotiations. However, in her writings on gender and madness (and elsewhere) Minkowitz is explicitly transphobic. This is in direct contradiction to my theoretical and ethical principles. While I cannot ignore Minkowitz’s work, I cite her with reluctance. This footnote serves to call attention to the exclusionary and hateful underpinnings of some of her work.

UNCRPD, violence and discrimination are framed as a result of impairment. However, mental impairment is often caused by violence and abuse and cannot be seen as neutral, acultural, and atheoretical (Penson, 2015; Plumb, 2015). Penson (2015) argues for a double social model of disability where both impairment and disability are subject to social forces. Third, experiences diagnosed as symptoms of mental illness are not necessarily experienced as impairments but rather can be potentially positive experiences (Plumb, 2011). However, these authors do not engage with postcolonial disability studies (which explicitly frames impairment as socially produced) and crip theory (which challenges the binary of impairment vs disability). Bringing in these bodies of literature opens new pathways to resolve the tensions between survivor research and the social model of disability.

Researchers have also highlighted key differences between the experience of physical disabilities and psychosocial disabilities. Mad people or “expressions of unreason” elicit pathologisation, vilification, and coercion from society (Penson, 2015; Plumb, 2015; Spandler & Anderson, 2015; Tew, 2015). Thus, claiming a disability identity presents a conundrum—access disability benefits and accept pathologisation, or resist it and be denied disability support. This dilemma is mitigated somewhat by the inclusion of the ‘imputed/attribution’ disabilities within the UNCRPD. This enables the extension of its protections to those who face discrimination on the basis of being *perceived* to have a disability and/or an impairment by society (Minkowitz, 2015; Spandler & Webb, 2015).

The very nature of disability support required is also contested. Due to its focus on access and reasonable accommodations within existing societal structures and norms, the UNCRPD cannot deliver the radical change demanded by the user/survivor movement (Plumb, 2015; Reeve, 2015). Donna Reeve (2015) draws a distinction between structural disablism—due to lack of access mechanisms such as ramps, braille, etc.—and psycho-emotional disablism—due to stigmatising actions and comments. According to them, physical disability activists are concerned only with the former while user/survivor activists need to address the latter. This binary ignores the complexity within the experience and marginalisation of physically disabled persons. Further, this framing leaves no room to address structural discrimination written into laws restricting employment, marriage, and financial control which are common in the global South (Davar, 2015c). Reeve’s (2015) argument obscures the heterogeneities within both disabled and mad experiences and underlines the narrow scope of this literature and its inapplicability to other contexts (Jones & Kelly, 2015). My intersectional lens and cross-disability investigations offer ways to side-step the physical/psychosocial and structural/emotional disablism binaries.

Jan Russo and Shulkes (2015) examine the records of the European Network of Users and Survivors (ENUSP) to trace some of the debates on disability within the organisation. They provide a valuable reminder that any debate on a disability identity is deeply personal for users/survivors who continue to experience marginalisation and abuse by including their own personal reflections on the issue. They make two pertinent observations. First, a disability identity elicited opposition within the ENUSP because it was externally imposed as a strategy to achieve organisational goals. This undermines the collective user/survivor struggle to define their own reality and experience. This mirrors the opposition to an imposed user/survivor identity in the global South (Davar, 2018).

Second, they contextualise their discussion by considering the financial precarity and poverty, only partially mitigated by disability benefits, within which questions of self-definitions and theories of madness and disability emerge. Russo and Shulkes (2015) situate the centrality of the UNCRPD within the broader context of political influence, availability of resources and funding, and coalitions dependent on capacity building. Activism, pedagogy, and advocacy do not happen in a vacuum and the possibilities of exploring conceptual and methodological approaches which reconcile madness and disability is hindered or facilitated by the socio-political specificities of the context (Church, 2015). A situated understanding of how psychosocial disability traverses and is constituted within activism is thus key to creating a disability framework of madness and cannot be divorced from its context.

### *Beyond the social model of disability*

There is an acknowledged need for adaptations or alternatives to the social model of disability to reconcile madness and disability. Some authors argue there is no need to create a delinked model of madness and disability since the social model of disability “is not set in concrete and finalised, never to change” (Spandler & Webb, 2015, p. 154) and a variation of the model can accommodate madness (Beresford, 2015; Beresford et al., 2010; Minkowitz, 2015). Others have looked elsewhere for inspiration such as concepts and models from development studies (Wallcraft & Hopper, 2015); neurodiversity movements (Graby, 2015); and disability concepts such as psycho-emotional disablism (Briggs & Cameron, 2015; Reeve, 2015; Tew, 2015).

Some scholars have argued that a “single frame of analysis” is inadequate, and we must turn to intersectional thinking to generate inclusive user/survivor and disability scholarship and activism (Barker & Iantaffi, 2015; Keating, 2015). Current user/survivor critique of the social model of disability as well as the social model of disability itself centre whiteness (Keating, 2015). They do not account for how racism, geopolitics, and indigeneity mediate disability and/or madness.

Frank Keating (2015) and Barker and Iantaffi (2015) highlight the potential of critical race theory, feminist and queer theory, crip theory, and critical disability studies to move the debate about madness and disability forward, to avoid reinventing the wheel, and to be more inclusive.

Overall, survivor research attempts to untangle what psychosocial disability could mean and how understandings of psychosocial disability might fit with existing models of disability. It successfully centres the voices of those deemed mad. With a few sparse exceptions, it does not engage with structures of oppression beyond psychiatric and medical establishments. This leads to and is a consequence of centring only a small subset of voices at the expense of others. The marginalisation of racialised people and communities and those in the global South within survivor research also leads to a lack of engagement with other bodies of literature—crip theory, abolitionist scholarship, postcolonial disability studies—which have centred these voices.

The four discrete bodies of literature I have reviewed frustratingly remain siloed from each other. It is clear from my literature review that there is no in-depth empirical examination of psychosocial disability. Bodies of disability literature on/from the global South are not concerned with psychosocial disability and survivor literature on psychosocial disability is not concerned with the global South. The small body of literature on psychosocial disability does not engage with critical disability literature. This is not just a key gap; rather it lends itself to tell a single story of psychosocial disability—as an identity forged in defiance of the North-centric survivor movement, tied to legal instruments and state-centred rights, which liberates us from the chains of oppression of psychiatry. This is not just a partial story; it is harmful one. It excludes any examination of power dynamics *within* the psychosocial disability movement; it dismisses the lived experience of those who live at the intersection of multiple oppressions, including oppression by the state; it does not allow for unpacking the constraints of operating within the structures of the international disability movements; and it leaves no room for other stories of psychosocial disability. Informed by crip theory and critical disability studies, as well as other intersecting bodies of scholarship and guided by the theoretical principles detailed in the next section, my empirical examination of psychosocial disability as understood and ‘done’ by activists in India will attempt to fill the gaps in the literature and trouble/extend the single story of psychosocial disability.

## **2.2 Theoretical principles**

This thesis lies at the intersection of several bodies of theory and literature. It intentionally and purposefully refuses to apply any rigid theoretical framework to guide it. Grounding the entire thesis within any specific theoretical framework would run counter to the politics and values of



my thesis, i.e., centring and being led by the work of activists with psychosocial disability in the global South. I do this not to dismiss the value of theory and theoretical frameworks, but rather as an acknowledgement that multidisciplinary work must draw upon a plurality of concepts to ground itself. This section outlines the concepts I draw upon.

As is common in social movement, decolonial, and some postcolonial scholarship, I understand social actors as epistemic actors and their practices as sites of knowledge production (Casas-Cortés et al., 2008; Escobar, 2009; Icaza & Vázquez, 2013). Specifically, and in a single sentence, my thesis is grounded within an understanding that mad people, especially those who are multiply marginalised, generate new knowledge about structural understandings of disability through their activism and social movements. This section unpacks the theoretical history of and contemporary thought around three parts of this central idea. First, I draw upon survivor research and its critiques as well as other bodies of literature to highlight conceptualisations of Mad people as epistemic actors. Second, I borrow from decolonial literature and social movement literature on knowledge production to posit that activism is a valuable site of knowledge production<sup>24</sup>. Finally, I draw on Disability Justice frameworks, crip theory, and crip-of-colour literature to put forward that disability is structurally, materially, and discursively constructed. These three principles bring together critical understandings of marginality, knowledge production, and disability. All three of these principles are essentially concerned with the “geo-politics of knowing. Who and when, why and where is knowledge generated” (Mignolo, 2009, p. 160).

### **2.2.1 Mad people as epistemic actors**

The exclusion of mad people, or those deemed mad, as creators of knowledge has been the driving force behind the emergence of survivor research as a field. It contests the claims of objectivity and universalism which underpin psychiatric knowledge. It challenges the exclusion of users/survivors/persons with psychosocial disability, based on their lack of reason and

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<sup>24</sup> I use the word borrow purposively, instead on grounded in, or even rely on. While I cite scholars using decolonial theory, this project is not a decolonial project. My project is still based within the nation-state idea of India and uses ‘psychosocial disability’ and the activists using that phrase as its starting point. An alternative framing closer to decolonial lens would not be bound by the colonially imposed borders of the nation-state and would focus on broader understandings and mobilisations of political disability and madness. What I am doing here in referring to decolonial thought is an act of borrowing, not one of adoption. As Eve Tuck & K. Wayne Yang (2012) remind us, decolonisation is not a metaphor. Adoption of decolonial theory or framing this project as a decolonial project would necessarily mean undertaking the political and material work of dismantling colonial centres of power, including universities, which I have not done. This footnote is a reminder to me and to the reader, that borrowing becomes co-opting when we de-link work from its political aims. This footnote is a reminder of those political aims.

rationality, from the realms of knowledge generation (Faulkner, 2017). Survivor research has much in common with the project of disability studies, particularly its insistence in challenging individualised medicalised models and discourse and foregrounding experiential knowledge. (Faulkner, 2017; Russo & Beresford, 2015). However, there is a paucity of deep engagement with disability studies within survivor research, at least in the UK. A newly emerging field in Canada, Mad Studies which is “a project of inquiry, knowledge production, and political action” is attempting to create cross-disciplinary links with disability studies and other disciplines (Menzies et al., 2013, p. 13).

Some survivor researchers have utilised Miranda Fricker’s framework of ‘epistemic injustice’ to conceptualise the epistemic exclusion of user/survivors/mad persons (LeBlanc & Kinsella, 2016). Epistemic injustice focuses on how a person’s capacity as a knower is undermined by injustices related to “our most basic everyday practices: conveying knowledge to others by telling them and making sense of our own social experiences” (Fricker, 2007, p. 1). Miranda Fricker (2007) outlines two forms of discrimination which result in epistemic injustice: testimonial injustice and hermeneutical injustice. Testimonial injustice occurs when a person’s words and knowledges are discredited based on prejudice and discrimination. People with psychiatric diagnoses are not seen as “credible reporters or witnesses of our own experiences” through institutionalised psychiatric practices as well as interpersonal engagements driven by stigma (White, 2018). Hermeneutical injustice refers to injustices which lead to “some significant area of one’s social experience obscured from collective understanding” (Fricker, 2007, p. 155). Power imbalances affecting access to sites and means of knowledge generation and what constitutes knowledge tend to privilege psychiatric (and other psy-sciences)<sup>25</sup> knowledge while excluding knowledges generated by those deemed ‘mad’.

Survivor research and Mad Studies both create knowledge from a shared marginalised position of madness and distress, but like with many other fields, the conceptual and material differences within that marginalised location are often flattened (Voronka, 2016). In common with other social movements, the user/survivor movement (and scholarship) has “an inherent danger of allowing the narrative...to be dominated by individuals who are normative in all other senses, thereby marginalising non-normative voices within the group” (Faulkner & Kalathil, 2012, p. 46). Drawing a parallel with Chris Bell’s critique of what he called ‘White Disability Studies’, Rose and Kalathil (2019) note that “in the making of mad knowledge, whiteness still prevails” (p. 8).

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<sup>25</sup> Psy-sciences encompass knowledges and practices from psychiatry, psychology, psychotherapy, and other related fields. It understands these fields as interdependent and founded on similar epistemic foundations.

Those at the intersection of madness and racialisation face epistemic oppression by Western psychiatry as well as epistemic exclusion or neglect by a white-dominated survivor research and Mad Studies (Bruce, 2017; White, 2018). Kalathil and Jones (2016) argue that survivor research and Mad Studies have done little to counter the “colonial mentalities” within academia and activism and have neglected to address their Eurocentricity. These approaches have been largely concerned with the politics of knowledge production but only insofar as it relates to mad people. This is apparent from the paucity of conceptual or empirical literature tracing the contours of user, survivor, mad, and psychosocial disability knowledge in the global South and within this silence lies another form of epistemic injustice.

The need for a global South generated framework of madness and distress has been clearly set out by Davar and other activists as a driving force behind the emergence of ‘person with psychosocial disability’ as an identity location (Davar, 2018). Many scholars across diverse disciplines have critiqued the “claim to universality” of Western knowledge which insists on a singular universal framework at the expense of epistemological diversity (Connell, 2011; Nguyen, 2024). For madness to be repackaged under the auspices of Western psychiatry and either imposed or sold to the people of the global South renders the mad colonised subject doubly silenced, and in the process suppresses the different ways of being mad and understanding madness (Mills & LeFrancois, 2018).

The global South, for me and others, is not a geographical entity but rather an analytical one, “created, imagined, invented, maintained, and recreated by the ever-changing and never fixed status positions of social actors and institutions” (Kloß, 2017, p. 1). As such and as many scholars have pointed out, it is not homogenous, there exist Souths within the North, and Norths within the South (Krotz, 1997). It is the South within the South that particularly interests me. By that I mean, those peoples who are excluded from and oppressed by movements which claim to challenge colonial structures. If, as is argued, that knowledges from such marginalised locations can make “the politics of knowledge and the power investments that go along with it visible...” (Mohanty, 2008, p. 511), the knowledges that emerge from these multiply marginalised locations enable an interrogation of the way power shapes and operates within the psychosocial disability movement in India (Ghai, 2002). In other words, mad people within the global South, especially those experiencing multiple forms of marginalisation, are epistemic actors and their knowledges are valuable in shedding light on issues and dynamics that are otherwise obscured.

### 2.2.2 Activism as a site of knowledge generation

A critique of Western knowledge systems includes a critique of the differential values placed on knowledges emerging from different sites. Western, and often Anglo-centric, academia is understood to be the primary and most rigorous site of knowledge production, particularly theory (Fúnez-Flores, 2024). This is part of the same colonial system of privileging some knowledges and dismissing others. The global South and non-academic sites of knowledge generation, within this system, are treated as places for data extraction, somewhere where academically produced theories can be applied or tested, described and analysed for distant audiences. For Nguyen (2024), “learning *with* and *from* the spaces where marginalised people from the global South have experienced colonisation and exclusion is an important initial step towards” challenging epistemic injustice (pp. 238, emphasis in original).

Realms of marginality are also often realms of resistance, whether that is the everyday acts of resistance or the project of collective movement building. As Josh Platzky Miller (2019) argues, social movements and political activism are “critical conduits for epistemic acts” (p. 55) and the “theories and practices forged within...struggles are invaluable resources” (Vergès, 2021, p. 19). Building on the work of José Medina (2013), Lorena Reinert (2020) makes a similar intervention about the importance of “knowledge frameworks that challenge oppressive structures and the ideologies that sustain them” which emerge from and through collective political struggle (Medina, 2013; Reinert, 2020, p. 38). They term these “epistemologies of resistance”, and it is these epistemologies of resistance, i.e., knowledges borne out of and through struggles against oppression that I foreground.

Social movement studies is increasingly acknowledging and recognising knowledge generation by and within social movements and activism. Similar to the arguments above, some global South social movement scholars argue that those who suffer the most under the interlinked systems of racial capitalism, colonialism, and other systems of oppression have privileged knowledge about them (Cox, 2014; Cox & Flesher Fominaya, 2009). Therefore, social movements as sites of resistance against these oppressive systems “have long been the bearers of knowledge about forms of oppression and injustice, expressing political claims, identifying social and economic grievances and bringing new or neglected issues to public prominence” (Chesters, 2012, p. 153). Through their collective work, they generate knowledges about understandings of specific oppressions, methods and strategies to challenge those oppressions, and finally, potential solutions. Acknowledging movement and activist knowledges as valid and valuable moves us

closer to embracing a plurality of knowledges, further undermining the cause of a singular universal academically produced knowledge.

My reluctance to impose a rigid theoretical framework derives from a refusal to create hierarchies between academia as a site of theory generation and movements as the site of empirical data. Movements and activism, for me and for scholars from varied fields and disciplines, generate wide and varied forms of knowledges, including theoretical insights about the issues they are concerned with and the larger systems within which we are all operating. The relationship between research and movements is contested, and the line between recognising and privileging activist knowledges and extracting and devouring them is easily crossed (Mukherjee et al., 2011; Otto & Terhorst, 2011). Academic research can and does undermine its own prominence as long as it is “learning *with* and *from* the [activist] spaces” and their epistemologies of resistance (Gomes de Matos, 2015; Nguyen, 2024, p. 238, emphasis in original). Aligned with the work outlined above, I understand activism, in this case mad and disability activism, as not just valid and valuable, but rather as privileged sites of knowledge generation.

### **2.2.3 Disability as an intersectional structural issue**

As the first section of this chapter outlined, disability has been understood and conceptualised in many different ways. I understand disability as an intersectional and structural issue which requires intersectional activism aimed at structural causes of oppression. This understanding is rooted within the work of activist initiatives such as Sins Invalid and frameworks such as Disability Justice, an intersectional framework of disability activism created by Black, brown, queer, and trans members of the Disability Justice Collective, as well as within scholarship from crip, abolitionist, postcolonial, and critical disability scholars<sup>26</sup>. Disability Justice emerged as a challenge to the disability rights movement which provided much-needed visibility to (some) disabled persons but simultaneously neglected the experiences of people who live “at intersecting junctures of oppression” (Berne, 2015, para. 7). Disability Justice is concerned with how different intersecting systems of oppression work together to exert violence against disabled peoples as well as create and produce disability. There are three foundational aspects of such a theorisation of disability that are central to my enquiry: one, disability as fluid and evolving; two, structures of violence as creators of disability and impairment; and three, the intersectional nature of said structures.

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<sup>26</sup> I use Disability Justice (capitalised) when referring to the specific framework by Sins Invalid. I use disability justice (in the lower case) to refer to the broader practice of justice-based (as opposed to rights-based) disability activism.

First, informed by crip theory, I take an expansive and inclusive understanding of disability which is concerned with how and why certain bodyminds come to be seen as disabled (Kafer, 2013). Moving away from rigid identity categorisations of disabled vs nondisabled as well as categorisations within disability, I understand disability as evolving and fluid with diverse articulations. This diversity is of particular importance to mad people who have often been left out of or neglected by traditional disability studies due to the predominance of able-mindedness within academia (Price, 2011). Crip understandings of disability as well as understandings which emerge from activism, which is what I align with, understand disability as inclusive of all non-normative bodies and minds, including those considered ‘mad’ (Sandahl, 2003; Schalk, 2013). Furthermore and relatedly, in line with the entanglement of the material and the discursive in the discussion of epistemology above, my understanding of disability emphasises “reciprocal relationships between the discursive and therefore socio-cultural aspects of our experience as disabled peoples and our material existence in a disabling society” (Corker & French, 1999, p. 7). Disability in this way is inscribed both on our bodyminds and on the structures within which they exist.

Second and relatedly, I espouse a structural view of disability. I follow Southern disability scholars who understand both impairment and disability as socially produced and socially inscribed (as opposed to the social model of disability which views impairment as neutral). This mode of analysis, also espoused by Disability Justice and abolitionist frameworks, implicates systems of capitalism, state violence, colonialism, and injustice in not just the creation of disability but also impairment (Ben-Moshe, 2020; Meekosha, 2011). Within this framing, the state is not just a provider of rights (as under the disability rights model) but rather complicit in the production of impairment and disability. This structural mode of analysis allows me to unpack how psychiatrisation and medicalisation work with neoliberal policy, casteism, patriarchy, and military occupation to create distress and then obscure the reasons behind that distress (Addlakha, 2008; Kandukuri, 2018, 2020; Mishra, 2007; Soundararajan, 2022).

Third, I understand ableism as built into the foundations of several interlocking structures of oppressions (capitalism, white supremacy, heteropatriarchy, colonialism, amongst others). Dismantling these structures is key to achieving justice for all disabled persons (Berne, 2015). DisCrit, crip-of-colour, and Disability Justice hold that any analysis of disability which does not explicitly engage with how disability intersects with race and racism, colonialism and indigeneity, gender and heteronormativity, and capitalism and globalisation is incomplete. They build on the work of Black feminist activists and scholars and utilise intersectionality as a point of departure (Berne, 2015; Kim, 2017). Intersectionality puts forth that people’s experiences are shaped by

“many axes that work together and influence each other” (Collins & Bilge, 2016, p. 2; Crenshaw, 1991). Banerjee and Ghosh (2018) argue that without an intersectional analysis and praxis, movements tend towards an “unproblematic acceptance of a homogenous category” resulting in the “reproduction of margins and hierarchies” (p. 5). This is largely true of the mainstream psychosocial disability movement which has tended towards single-issue organising, undermining the possibilities of solidarities with other movements, as well as rendering the power imbalances within it invisible.

Intersectionality as a concept has garnered significant debate and critique in recent years globally and within India (Banerjee & Ghosh, 2018; Nash, 2019; Puar, 2012; Sen, 2023). Presenting the full scope of this debate is beyond the scope of the thesis. However, there are some points of contestation that are necessary to address. Detractors of intersectionality argue that the concept is too focused on rigid identities at the expense of structural analysis; that it is limited in its ability to address issues beyond race and gender; and that it has been co-opted and depoliticised and is now used widely as a checklist exercise by academics, NGOs, and businesses (Banerjee & Ghosh, 2018; Nash, 2019). I follow Disability Justice as well as the work of Dalit feminists in my mobilisation of intersectionality. Disability Justice explicitly expands the scope of intersectionality to identify and address a wide range of systems of oppression such as colonialism and capitalism. In their explanation of intersectionality, they state that “depending on context, we all have areas where we experience privilege as well as areas of oppression” (Berne, 2015, para. 15). Dalit feminists in India have long used intersectionality in their analysis and activism to not only address the co-constitution of caste and gender marginalisation (Brahminical patriarchy)<sup>27</sup> but equally mobilised it to include capitalist exploitation and coloniality (Kannabiran, 2006). The co-option and commodification of intersectionality is certainly widespread; however, others have argued that we cannot cede it entirely to neoliberal forces.

Intersectionality for me is a way to emphasise that the process through which some bodyminds are made available for impairment and disability and/or come to be seen (or not seen) as disabled is not the result of a single system which evenly affects everyone in the same way. Following Banerjee and Ghosh (2018), intersectionality, for me, can make “possible a political praxis of coalition-building by disorienting habits of essentialism, categorical purity and segregation in constituting movements” (p. 8). Within the Indian context, caste oppression,

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<sup>27</sup> Uma Chakravathy (1993) coined the term ‘Brahmanical Patriarchy’ where patriarchal society is organised based on Hindu caste system, where strict dictates of traditions, rituals, coercion, control, and violence are perpetuated to uphold the caste dominance, which emphasises controlling women sexually to maintain caste purity.

military occupation in the North-East and in Kashmir<sup>28</sup>, persecution of religious minorities, queerphobia, and marginalisation of Adivasi communities cannot be separated from ableism. Furthermore, the epistemic privilege of people who are most marginalised by unjust structures and “everyone who is marginalised in mainstream disability organising” enables them to understand and unpack how (and which) interlocking structures of oppression come together to cause disability (Piepzna-Samarasinha, 2018, p. 5). In other words, to uncover the complicity of these systems and untangling how they work and might be resisted is the work of those who live at the intersections of multiple marginalisations.

An intersectional and structural disability analysis for me is contingent on an expansive understanding of disability wherein intertwined systems of injustice and oppression come together to produce impairment and disability. The work of disability justice is intrinsically tied to dismantling all systems of injustice. My enquiry hence “start[s] with disability but never end[s] with it” (Goodley, 2013, p. 632).

In summary, the theoretical principles which underpin my thesis are necessarily concerned with issues of knowledge generation—who, where, for what purpose, under what circumstances, and about what. My thesis relies on the principle that people deemed ‘mad’ or people with psychosocial disabilities living and working at the intersections of multiple marginalisations generate knowledges through their activist practices that not only adds to or intervenes in disability theory but rather creates new avenues of disability theorisation.

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<sup>28</sup> The North-East region of India, comprising eight states, face multiple forms of violence including resource extraction from the Indian state. It has distinctive cultural, religious, ethnic, and linguistic traditions and its communities face discrimination. Since India’s independence, some political movements in the region have demanded autonomy. The Indian state, using the language of insurgency and conflict, has deployed the military in parts of the region to keep ‘order’. It has imposed the Armed Forces (Special Powers) Act 1958 (AFSPA) in the region which allows armed forces to conduct searches, arrests, and use violence. Under the Act, the actions of the military can only be addressed through military court. The militarisation of the region has led to, and continues to lead to, gross human rights violations. For more refer to Kikhi, Das & Dutta (eds.) (2023) and Kadena (2024).

Kashmir is a site of significant militarisation by the Indian state. Different parts of Kashmir are administered (or occupied) by India, Pakistan, and China. Indian occupied Kashmir is one of the most militarised areas of the world. As a response to the Kashmiri demand for a referendum on independence, the Indian state has imposed a brutal regime of military occupation, forced disappearances, torture, communications blackouts, and a host of other repressive actions. In 2019, the Indian government abrogated Section 370, a provision which gave the state of Jammu & Kashmir autonomy over some of their affairs. The abrogation is an escalation of the long-standing Indian state’s repression of Kashmir. For more refer to Hafsa Kanjwal (2023) and Ather Zia (2019).



### **2.3 Research questions**

My thesis aims to create new understandings of psychosocial disability that have been derived from/with/through activism in India and poses the following questions:

1. How is psychosocial disability constituted and understood by activists with psychosocial disabilities in India?
2. How is psychosocial disability mobilised and ‘done’ and for what purposes with respect to the institutions and discourses which govern it?
3. How is psychosocial disability ‘done’ and for what purposes within the psychosocial disability movement itself?
4. What possibilities, futures, and pathways lie within psychosocial disability activism at the margins and how are they understood and ‘done’ by those who occupy these margins?

The first question focuses on how psychosocial disability is understood and constituted. The literature touches upon psychosocial disability as an identity and as a category. Davar (2018) describes psychosocial disability as a collective and political identity location which rejects and challenges the imposed identity of ‘patient’. Priestly (1999) argues that identity is constructed through “a variety of disciplines and discourses (many of them institutionally embedded)” as well as through “self-knowledge and by speaking about ourselves” (p. 94). I aim to understand how, and in what spheres, do activists construct a psychosocial disability identity. I understand identity as fluid and context-specific wherein collective, political, and personal identities are enmeshed (Crenshaw, 1991).

Psychosocial disability, in its most visible narrative, came into being as a disability category through its explicit recognition of the UNCRPD. Within national legislation, psychosocial disability is a category of disability. Several scholars have troubled the idea of categorisation (Alejandro, 2021; Friedner et al., 2018; Mills, 2015; Potter et al., 1993). However, the medico-legal structures associated with disability have produced and perpetuated disability as a category (Kohrman, 2007). Crip theory, however, challenges the bounded nature of disability as a category and explicitly includes and enables the inclusion of all non-normative bodyminds (Price, 2015; Schalk, 2013). Friedner et al. (2018) remind us that “inclusion in the disability category thus always has a constitutive outside” and ask, “who is included and on what grounds” (para. 6). It is this question that I am interested in when examining psychosocial disability as a category. Where are the boundaries of ‘psychosocial disability’ as imagined by activists? Who is excluded, and what does that exclusion do for psychosocial disability activism? How, if at all, are these boundaries and exclusions reflective of institutional frameworks (such as legislation and

diagnosis)? In Chapter Four, I ask and answer my first research question and examine psychosocial disability as an identity, as a category, and uncover new ways of understanding psychosocial disability.

The second research question is concerned with how psychosocial is mobilised and ‘done’ with respect to the institutions and discourses that govern it. It follows from an understanding of discourse as a social practice which limits and facilitates not just what can be said, but what actions can be taken (Foucault, 1980; Hall, 2001; Swerdfager, 2016). This research question is about the actions that are made possible by psychosocial disability frameworks and identities and the actions that come to constitute psychosocial disability activism. It is concerned with whose interests these actions further and whose interests are excluded. These issues will be addressed in Chapter Five, unpacking psychosocial disability in relation to psychiatry, human rights, and the state.

The third research question follows from the second but looks inwards towards the psychosocial disability movement itself. It is concerned with how people organise themselves and how they understand these ways of organising, the forces and systems which make some ways of organising possible and foreclose others, and their personal, political, and epistemological implications. The question of how psychosocial disability is ‘done’ and for what purposes within psychosocial disability movements is addressed in Chapter Six.

The fourth and final research question delineates the less visible, the marginalised, and the non-mainstream ways of understanding and doing psychosocial disability. While all empirical chapters are shaped by knowledges from the margins, this question is addressed in detail in Chapter Seven. It explores the ways psychosocial disability can be understood and done, despite the material and discursive constraints of the structures detailed in preceding chapters. It ends with reflection on the ways might psychosocial disability from the margins extend/disrupt/trouble mainstream disability and psychosocial disability activism.

### *Interlude: on writing*

*I was trained as a clinical psychologist and then in global mental health. I was taught to write in the third person, never using the ‘I’, keeping myself, ‘the researcher’, anonymous. The only other writing I have practiced consistently has been diary entries (and some horrifyingly embarrassing blog posts in my teenage years). Written the way I speak; these broke all the rules of ‘correct’ English I was taught—grammar and tenses. Formal and professional. Commas have purpose. It doesn’t matter how much you like an em dash, it is not always appropriate.*

...

*When I read this thesis in full, I sometimes get whiplash from the different affective registers in different sections and chapters. Some parts feel so intimate and others so distant. I continue to unlearn everything I have been taught about the ‘right’ way to write and practice using my voice and it is all a work-in-progress.*

...

#### *“I, we, them”*

*These words have plagued me and the kind people who helped me proof-read. I am a researcher, distanced from my interlocutors—there is an ‘I’ and a ‘them’. But I also share so much with them: their dreams, their critiques, their frustrations—there is only ‘we’.*

*And then there is the movement at large, of which we are all a part (interlocutors, me, the people we critique)—we, the psychosocially disabled.*

*And then again, the really big ‘we’—we, who believe in and fight for justice. I have clarified which ‘we’ I am using sometimes, but for the most part I have left it up to the context to explain it. I, like everyone else, am part of many webs and slip in and out of them, and as such so do my I’s, we’s, and them’s.*

...

*I write from madness, but I will not give every piece of knowledge I make from madness to academia. There is no room in academia that would not shatter at the sound of the primal scream which is madness or be able to hold the rage and joy and dance in it. But I will also not reduce my madness to screams and dancing. I write from a place of madness in the entirety of this thesis, whether it is in these interludes or in my analysis of disidentification and utopian thinking. I write from a place of madness in every movement and at all moments in my life. And I will not give it all to academia. It does not deserve it.*

### **III. Disability as method: contradictions and complexity**

For the last two years of the PhD, I was a Graduate Teaching Assistant (GTA) on the module Qualitative Research Methods, an introductory methodology course offered to students across the university. Many of the students came from quantitative backgrounds, with little or no experience in qualitative research methods. By necessity, the module is a whirlwind tour of different aspects of qualitative research and does not pause often to discuss the subtleties of research. I enjoyed teaching the module and learned a lot from my students' questions which seemed basic at first but forced me to think about the foundations of research methods, analysis, ethics, and reflexivity. However, it proved to be challenging in ways I had not anticipated. While I was attempting to do research which reflected the political values of this project—centring disability, navigating complex questions of researching with friends and comrades, thinking of knowledge production as a collective project, challenging ableism in the academy—I was also enforcing the rules of the module—rigid ideas about vulnerability, not interviewing friends, and policing attendance. It was a microcosm of the larger contradictions of doing disability research within the hyper-ableist atmosphere of the university.

This chapter describes and reflects upon the methods I used to answer my research questions. Some part of the methods I outline here were driven by theoretical principles; some emerged through the research process itself; and others were dictated by feasibility. Despite these different ways my methodology was shaped, I understand methodology as an explicit political practice. My methodology served to answer my research questions in congruence with theory, but equally it was dictated by the political values of the project. For me and this project, this meant it was essential that every step of the research process was embedded in the understanding that disability is only one axis of exclusion, one that cannot be disentangled from other axes of oppression and marginalisation. I strove to (and hopefully succeeded in) writing honestly and transparently about the decisions and conflicts I faced and the reasoning behind my methods of addressing them or as it turned out sometimes, not addressing them.

The first section of the chapter outlines the two key principles which shaped my research methodology—disability as method and iterative research. Explaining how my research embodies these principles, I then outline my data collection process, followed by the theory and method of my analysis. I close the chapter with a section on procedural ethics and reflections on positionality.

### **3.1 Methodological principles**

The principles outlined in this section emerged partially through engagement with scholarship and theory and partially through the process of doing the research itself. The sections which follow refer back to the examples and ideas central to the two main principles I describe here—disability as method and rejecting linearity.

#### **3.1.1 Unpacking ‘disability as method’**

Disability studies is now well established as a discrete discipline and field of study. In the last few years, however, many disabled scholars have begun to understand disability as method, i.e., disability not just as a subject of research, but as a way to do research. Like survivor research does for users and survivors, disability as method centres “disabled ways of thinking, knowing, and telling” (Mills & Sanchez, 2023b, p. 10). Julie A. Minich (2016) in their argument that disability studies is a “mode of analysis” outlined three ways in which disability as method, or as they call it critical disability studies (CDS) as methodology, is operationalised.

The first, according to Minich (2016), “involves scrutinising not bodily or mental impairments but the social norms that define particular attributes as impairments, as well as the social conditions that concentrate stigmatised attributes in particular populations” (para. 6). Bridging theory and method, this aspect of disability as method rejects the idea of a universal or inherent disability located within an individual. Rather, for a project built on disability as method, it is essential to view disability and impairment as socially produced. In this way, disability as method puts “disability in conversation with other concepts and worlds” (Friedner & Weingarten, 2019, p. 485). My thesis centres activists who embody and utilise psychosocial disability as a concept to challenge understandings of mental (ill)health as purely medical conditions or diagnoses. This principle is built into its very foundations. I, and the people I interviewed, understand the boundaries of ‘madness’ as socially, politically, economically, and culturally produced and are engaged in challenging the bodies of knowledge that seek to pathologise difference. We are not mad and disabled, rather we are made mad and disabled through a range of “social conditions”, beyond ableism and sanism<sup>29</sup>, such as gender norms, capitalist ideas of productivity, casteism, and others which then come together to mark our bodies and minds as aberrant.

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<sup>29</sup> ‘sanism’ is a system of discrimination and oppression which “makes normal the practice of discrimination, rejection, silencing, exclusion, low expectations, incarceration, and other forms of violence against people who are othered through mental ‘illness’ diagnosis, history, or even suspicion” (Meerai et al, 2016, p. 18).

The second aspect of CDS as methodology explicitly links knowledge production and research to the goals of disability activism including but not limited to disability rights movements and disability justice initiatives (Minich, 2016). The focus of my work is on activists and the psychosocial disability movement and challenging the idea of academia as the primary site of knowledge production. My research questions arose through my previous engagement within the psychosocial disability movement. Beyond these links to activist knowledge production, I would like to understand this thesis as a peripheral branch of a collective activist and knowledge-making psychosocial disability project. However, this positioning is not without discomfort. A PhD is structured as an individual achievement, and as such, is in contradiction with the inherent collectivity of movement knowledges, and particularly with disability knowledges which are created in community with each other (Piepzna-Samarasinha, 2018).

Attempting to address this contradiction is part of the third aspect of CDS as methodology—disrupting ableist and inaccessible research and pedagogical practices (Minich, 2016). In the absence of accessibility measures (such as attendance, seating, lighting, etc), we cannot claim to be ‘doing’ disability studies no matter how non-normative and radical the content of our study might be. This is an uncomfortable truth that was brought into sharp focus every time I have filled out an attendance register or enforced a submission deadline as a teacher; and as a researcher whenever I have performed the hyper-productivity demanded by academic institutions.

Survivor researchers have often remarked on the academy’s focus on rationality and its exclusion of those who are deemed mad and seen as the epitome of ‘unreason’ (Armes, 2009). Likewise, disability theorists have challenged the assumption of able-bodiedness within an academic culture which rewards speed, efficiency, and results (Lau, 2020). This unholy combination of sanism and ableism is further exacerbated by the neoliberal focus on productivity and by the deteriorating labour conditions in UK universities, demanding that academics and students perform a sort of ‘super-abledness’ in order to succeed (Lau, 2020). It is within this context that I, and other disabled researchers and students strive to bring about change while also survive the demands of the academy. It is critical to understand ableism as an axis of exclusion which intersects with other marginalising conditions. Financial precarity and institutional vulnerability of junior staff and students as well as other external institutional barriers such as visa policies and access to benefits affect the most vulnerable members of the academy (Papoulias & Callard, 2022). For me and this research project, it means that I am in a constant state of balancing my needs with institutional expectations and demands. Throughout this PhD, I have often told myself and others that I have been very lucky with my supervisors and that they have always had

my back. Beyond being true, this statement also reflects my dependence on those who have more institutional power as well as my need to be innovative about ways to “overcome and outsmart the ableist demands of academic life” (Lau, 2020, p. 16).

I asked my participants how they navigate the discriminatory structures around them, how they challenge them. I ask myself the same question—how did I challenge, if at all, the ableist structures of the university? It is a task which I could only manage to tackle in a patchwork and partial way, if at all. Crip authorship, crip negativity, cripepistemology, and crip failure are all concepts which are part of the broader scholarship on doing disability as method (Johnson & McRuer, 2014; Mills & Sanchez, 2023a; Smilges, 2023). They make room for failure and negativity; the uncomprehensive and the incomprehensible; and the very real contradictions of trying to survive a system while also trying to dismantle it. Representing these conflicts honestly as they arose in my research, without performing the all-knowing confident researcher, is for me part of doing disability as method.

### **3.1.2 Rejecting linearity**

My research design was, both by design and necessity, iterative. I constantly revisited key decisions about who and how many people I interviewed, what questions I asked in the interviews, and the shape and design of the interviews. I conducted analysis concurrently with the interviewing process which shaped later interviews. This type of iterative research is not uncommon at all within qualitative research more broadly and is an essential part of doing research with disability as method (Kapiszewski et al., 2022).

Rejecting and/or challenging linearity is a deeply familiar part of disabled lives and disability literature. The lives of disabled people, particularly psychosocially disabled people, are often narrativized using neat stages of life—normalcy, illness, struggle, treatment, recovery. In a similar vein, the history of disability is told linearly as the world moves from more oppressive models of disability to more liberatory ones—charity model, medical model, social and rights model (Hamraie, 2015). Both imply the existence of an endpoint that is not only better and to be aspired towards, but is also distant and distinct from stages that precede it. Anand (2016) puts forth that the “progressivist routine that [disability studies] scholarship is imbued with” does not consider how disability functions in the lives and politics of the global South and seeks to foreclose the possibilities of disability scholarship that embrace messy contexts (p. 37).

Furthermore, embracing iterative research, for me, was also a practice of humility. What I set out to do in the beginning of the project was based on my reading of the psychosocial disability

movement, limited by my positionality, my social and professional networks, and by the biases present in what is published. Allowing my fieldwork to change those assumptions and hence my approach is not just a side-effect of research but a desired outcome.

My initial research proposal aimed to interview 25 psychosocial disability activists and 15 cross-disability activists, starting with those on the periphery of psychosocial disability activism and then on to the more visible and central figures in the movement. This research design was based on several assumptions—a marked separation between psychosocial disability activists and cross-disability activists; an uninterrogated use of the word activist; the somewhat arbitrary number of 40 interviews will be needed to get enough data; and finally, I need to or should interview the big names in the movement. Early interviews and preliminary analyses dismantled these assumptions. Some people I had categorised as cross-disability activists spoke at length about their experiences of psychosocial disability, identifying as both cross-disability and psychosocial disability activists. At the beginning of the project, I had two separate topic guides—one for psychosocial disability activists and another for cross-disability activists—and by the end, all my interviews used both of those topic guides and sometimes neither of them.

During my early overtures to potential participants, some people I viewed as activists refused to participate in the project because they did not see themselves as activists. This required me to reframe who I wanted to include in the project. Beyond that, it opened a whole new area of exploration—what constitutes activism? Later interviews explicitly addressed this point, and an entire empirical chapter is framed by the tensions presented by this question. I started adding a proviso to my initial emails/messages to potential participants—"the information sheet was written a while ago, my understandings of activism and activists have changed, I want to explore what activism means to you".

Finally, this project was motivated by the knowledge (and a hunch) that there was a significant amount of psychosocial disability work at the margins of the mainstream psychosocial disability movement. I was clear from the beginning that this was where I wanted to start and true to that, all of my early interviews were from/in those margins. However, I underestimated how many people and how much work was flourishing in what I had considered the periphery of the movement. My interlocutors, the majority of whom are located outside the mainstream, gave me a richness I had not anticipated. I never got to the arbitrary number of 40 or to the 'centre' of the movement.

Throughout the research process, many of the neat distinctions and the linear steps I had outlined at the outset collapsed. As I suspect is the case with most research, it became messy.



Part of my challenge in this chapter and throughout this thesis is to make that messiness intelligible without flattening it.<sup>30</sup> Messiness in the context of my research are those actions and knowledges, mine and those of my interlocutors, which do not lend themselves to fit neatly within frameworks, binaries, and/or categories. Methodologically, mess disrupts the dichotomy of success vs failure and of detailed planning vs adaptability. Rather, I see both success and failure as generative. For instance, refusal on the part of some potential participants to engage with the project enables me to understand the limits of a shared disabled/mad identity. As with all research, my methodological choices are founded on a set of values and principles but equally dictated by emerging findings and changing circumstances. Writing about my methodological choices as well as my findings and conclusions without attempting to fit them into a singular framework is, for me, a part of accepting messiness as generative.

### **3.2 ‘Crippling’ interviews**

To answer my research questions, I chose to do in-depth interviews with activists with psychosocial disabilities as well as those active in the cross-disability movement. I borrowed tools from critical discourse analysis to understand the intricacies of how psychosocial disability is understood, constructed, mobilised, and ‘done’ within disability movements in India. My interviewing process centred disability. Margaret Price and Stephanie Kerschbaum (2016) build on the disability justice principle of creating collective access to develop what they call an “interdependent accessible research paradigm”. They go on to describe the ways they ‘crippled’ research interviews, i.e., disrupted the ableist conventions of research interviewing by centring their own and their participants’ access needs. In the section below, I describe my account of “sideways, crooked, and crip ways of interviewing” (Price & Kerschbaum, 2016, para. 1).

#### **3.2.1 Why online interviews?**

I chose to use in-depth qualitative interviews, conducted over a digital platform, with people active in psychosocial disability and cross-disability movements as my method of data collection for a variety of practical, theoretical, and ethical reasons. Interviews honoured my participants as epistemic actors, enabled a broad reach of participants, and embodied disability principles in data collection.

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<sup>30</sup> My hunch is that “the problem is not so much lack of variety in the practice of method, as the hegemonic and dominatory pretensions of certain versions or accounts of method” (Law, 2004, p. 5). And as such, I do not claim a new method or even methods in the plural; only that this chapter aims to tell my account of method as honestly as I can.

Epistemologically, interviews supported my understanding of activists as epistemic actors who are best able to give an account of their processes of knowledge creation. My research is aligned with social movement scholars' understanding of activists as knowledge creators (Casas-Cortés et al., 2008; Cox & Flesher Fominaya, 2009; Escobar, 2009; Icaza & Vázquez, 2013). Other methods that have been utilised within similar research include analyses of documentary sources such as reports, blogs articles, and campaigning material. However, I am keenly aware that the production of such texts is inextricably linked to access to resources and platforms. The people I choose to interview are often excluded from certain platforms and resources because of their disabilities. Power imbalances within psychosocial disability activism themselves place limits on who is allowed to speak and what can be said. Further, the political landscape of India and the government's punitive measures against social justice activists have left activists, especially those from marginalised communities, in an extremely vulnerable position, further limiting what can and cannot be said in the public sphere (Roy, 2020). Within this context, interviews both enable me to move beyond the limited written and published accounts of the psychosocial disability movements and can address and redress the limitations caused by the exclusion of certain activists from the production of published knowledges.

Practically, this research project was conceptualised in and carried out within the context of the Covid-19 pandemic and interviewing as a method was very amenable to a move to a digital platform, mitigating the impact of the pandemic on the research process (Howlett, 2022). It reduced the risk to me, and to others, which would have arisen from my physical presence. Within the last few years, there has been a burgeoning body of literature about adapting research methods to online realms. A significant portion of these emphasise what is lost by such an adaptation—reducing our reach to those who have internet access and literacy, losing the ineffable and somewhat intangible impacts of occupying the same physical location, limiting visual cues, and risks of technical difficulties (Thunberg & Arnell, 2021). These concerns are valid and need to be addressed. For my project, the group of people I interviewed were likely to have access to the internet which mitigated one of the biggest concerns of digital research. Funding constraints as well as constraints related to energy and wellness would have limited my ability to travel across the country. The use of online interviews enabled a wider range of persons to be included within the project. Instead of reducing my reach, the use of online interviews increased the scope of the project. Despite these clear advantages, I, in line with many researchers, viewed digital interviews as a compromise (Thunberg & Arnell, 2021). Within the literature on digital research methods, researchers and scholars began to outline the benefits of digital research, some which I encountered—more participation, cost-effectiveness, and

scheduling flexibility. Very few, if any, of these reflections on digital research methods viewed them through the lens of disability.

Disabled people have long flourished in online worlds, forming communities and networks, organising together, and fostering friendships. People from other marginalised communities—queer people, people with limited ability to travel, networks engaging in trans-national solidarity, those affected by borders and visa restrictions—have also found variations of community through the internet. While many people and researchers, a past version of myself included, view online life as attempting to mimic ‘real-life’, for others digital worlds are part of their real lives and to view them as separate “would be to relegate these communities outside the realm of study” (Rogers, 2023, p. 93).

Many of my participants, even before the pandemic, socialised and organised online and doing interviews with them online was not awkward or unusual. It felt easy, natural, and accessible. As a disabled researcher coming to terms with my new chronic illness throughout the project, digital interviews provided an accessibility that I did not know I needed at the outset. They allowed for different forms of flexibility and intimacies. A few times, when energy faded for either me or the interviewee, we stopped the interview. We could do that easily and without the pressure of having to face another day of leaving the house, finding an accessible place to meet, and travelling to said place. We simply picked it up the next day or week or month. On the days I was really fatigued, I had the choice to forgo showering and changing out of my pyjamas and could use that energy for chatting with or interviewing people. Not only did this prove to be accessible, but it also created intimacies as I and my interlocutors laughed about our attempts to fluff our dirty hair to make it look better on camera; or hiding our comfy clothes with sweatshirts and scarves. We ate, drank, smoked, moved around, lay down, stretched while talking.

**Akriti:** Let’s talk about the disability movement in India. Oh God! I tried to hide my crappy T-shirt [both laughing] with this scarf, then I stretched...Is there a disability movement in India?

**Ambika:** Please do note that the moment you asked that question, I lit up my cigarette. Please do note that in your transcription.

**Akriti:** Love it. I’m just jealous that I can’t do that.

And of course, there were technical difficulties—I did two interviews with no video because of slow internet speeds. Sometimes there was a palpable dissonance between “the intimacy of our conversations and the remoteness of our bodies” (Rogers, 2023, p. 95). There were many

interruptions—doorbells rang, flatmates/partners/parents came by, pets appeared. And sometimes from my end, there was a deep yearning to occupy the same physical space as those I was talking to. Writing about it now, I also fear that digital interviews will be taken up not because of what they may offer or whether they are appropriate for a project, but because of cost-cutting by the neoliberal university. My account of doing digital interviews is not to advocate for or against them, but rather to understand digital interviews as a part of doing disability as method.

### **3.2.2 Finding and approaching interlocutors**

As stated above and in previous chapters, this thesis holds the position that knowledges emerging from marginalised locations including within the psychosocial disability movements are better able to make visible the entanglements of power and knowledge (Mohanty, 2008). Following from this and the Disability Justice principles of centring those most marginalised (Berne, 2015), I wanted to start my interviews with persons with psychosocial disability who are working at the intersections of oppression rather than with organisations and persons who are most visible in the psychosocial disability and cross-disability movements. For this project, this was a wide array of people—those working on issues of caste, queerness, gender; those who had left or were ousted from the mainstream psychosocial disability movement; those early in their activist journeys.

I identified my early participants by using my existing knowledge and networks and by scouring social media and blog sites for writings, organisations, and people who were working on intersections of caste, queerness, and disability. I then explained my strategy to each early interviewee and asked them for suggestions of other people I could contact. In methodological terms, I utilised a mix of purposive and snowball sampling (Douglas, 2022). I created a mapping document, populating it with names and details of potential participants; names of organisations and networks; and links to zines, blogs, podcasts, and websites. I updated the document throughout the project. At the current moment, it lists 59 people and 21 organisations. In total, I reached out to 34 people and ultimately interviewed 25 people. In last section of this chapter, I will reflect on the people I decided not to interview, those left out by the framing of the research, and those who refused to be interviewed.

Deciding who to include in the mapping document and who to approach for an interview depended on several key epistemological and methodological questions. The mapping document was broad—a person was included as a psychosocial disability activist if they had experience of psychosocial disabilities and were associated with psychosocial disability activism, advocacy,

scholarship, or movements. Persons who had engaged with psychosocial disability and cross-disability movements, activism, advocacy, scholarship but did not publicly identify as having a psychosocial disability were included as cross-disability activists. Along with their names and organisational affiliations, if any, I also noted details about their work, particularly if they worked on intersectional issues.

Deciding who to approach for an interview required me to breakdown several assumptions in my research framing. I was not aiming for a list of participants representative of the psychosocial disability movement, but rather to identify key persons who could provide historical and contemporary insights into the concept of psychosocial disability. The intention was not to use these interviews to characterise a general view of psychosocial disabilities. Rather, it was to seek out those working within different aspects of psychosocial disability and cross-disability activism to trace how the concept of psychosocial disability is constituted and actioned within these activisms. The three main aspects of my decisions were: person with psychosocial disability and for some, working on psychosocial disability; activist; and marginality.

- Person with psychosocial disability: Although the overall aim of the project was to understand how the framework of psychosocial disability is constituted and used by psychosocially disabled activists, I did not exclude someone if they primarily used a different term to identify themselves. This was done for two main reasons: First, the project is also concerned with who and what understandings are excluded from a psychosocial disability paradigm and some who choose not to use the term psychosocial disability could provide insight into that. Second, I aligned myself with a crip understanding of disability as fluid, evolving, and inclusive of “people with bodies and minds that are devalued or pathologised but who do not consistently identify (or are not consistently identified) as disabled” (Minich, 2016, para. 6). Towards these ends, I did not focus on the exact terminology they used to identify themselves or their work as long as two criteria were satisfied: one, they had some familiarity with the concept of psychosocial disability; and two, their work challenged madness/mental (ill)health as a purely medical category and reframed it as a social, economic, cultural, and political issue (Addlakha, 2013). For those who I identified as cross-disability activists, I used Meenu Bhambani’s (2018) description of cross-disability activism as that which works across, and is inclusive of, various disability and impairment categories.
- Marginality: This was a far more fluctuating and uncertain aspect of my decisions but there were a few guiding points that illustrate what I meant by marginality when it came

to interviewing decisions. Do they identify as working from a marginalised location (excluding disability) i.e., do they think of their work as being driven by their caste, sexuality, religious locations? Does their work itself address issues of cisheteropatriarchy, Brahminical supremacy, militarisation and occupation, Hindu nationalism and fascism? Are they in some form excluded by or ousted from the power centres of the mainstream psychosocial disability movement? If the answers to these questions leaned yes, I included them.

- Activist: Unexpectedly, this proved to be the trickiest aspect to define. I had planned initially to not place *a priori* limits on what constitutes activism and planned to include a potential participant if *they* identified their work as activism. However, as early as my second interview, it became very clear that the words ‘activism’ and ‘activist’ were more contested than I had imagined. There were people who I had thought of as activists, based on my understanding of their work, who professed reluctance in being interviewed because they did not see themselves as activists. I went back to my mapping document and tried to detail what held this diverse group of people doing wildly different types of work together. I came to the conclusion that they are all, without exception, challenging entrenched and dominant understandings and ways of ‘doing’ mental health. I understand activist, within the context of an inclusion criterion, as a person who understands the status quo as oppressive or marginalising and challenges it. While many people within their contexts contribute to challenging understandings of mental illness, for my project, it was important that they do so from a place of their own experience of psychosocial disability/mental ill-health, significantly narrowing the group of potential participants. A psychosocial disability activist, for me and within this loose understanding, is then someone who incorporates and mobilises their experience of psychosocial disability/mental ill-health to challenge and change dominant understandings of mental illness.

Of the 25 people I interviewed, all are currently based in urban areas and/or English-speaking but none of them see themselves as within the centre of the psychosocial disability movement. Throughout my thesis, I represent the mainstream psychosocial disability movement through its publications and through the eyes of my participants, many of whom have engaged with, worked within, and are connected to the mainstream movement. Some distanced themselves due to personal, political, or strategic differences; and a few were ousted. Some, especially those who position themselves within women’s movements, Dalit movements, and queer movements, prioritised working in those movements. All my participants have experienced mental distress,

mental (ill)health, disability, and/or psychosocial disabilities to some extent or another. Many of them have lived experience of marginalisations such as intergenerational poverty, caste-based oppression, religious minorities, military occupation, and geographical remoteness. Most engage in multiple forms of psychosocial disability work—they are artists, community organisers, writers, researchers, lawyers, teachers, and organisers. They work on grassroots initiatives such as awareness raising, peer support, and political mobilisation; engage with national level advocacy including consultations on disability and mental health policy and legislation; contribute to international and global level activism and advocacy; undertake scholarship and research within universities and beyond; and use art, writing (fiction and non-fiction), and poetry as their form of activism. Some work within human rights and advocacy settings, others work primarily within communities and collectives, and yet others move between different spheres of psychosocial disability action. Some work in long-existing organisations and others have chosen to create their own groups and collectives. A small minority of my participants have been working with issues of madness and disability for several decades.

Wherever they work, and whatever their relationship to mainstream psychosocial disability, all of them engage with disability intersectionally. Some of them engage with intersections which are largely ignored within disability movements—militarisation, queerness, sex work, trans rights, labour rights, DBA, anti-fascism, sexuality. Even amongst those who could be primarily described as working within the more common intersection of gender and disability, the exact focus of their work—pleasure, abortion, sex work—are less accepted within the mainstream. As such, all of them have special knowledge about psychosocial disability activism. In their attempts to create meaning out of their personal, political, and professional engagement with psychosocial disabilities, they engage with knowledges generated through activism, academic research, and theory.

I approached potential participants using email, social media, or WhatsApp with a request for an interview. The initial overture was also accompanied by an information sheet with a summary of the research project and an explanation of the interview process, a digital consent form, and a short list of topics to be covered in the interview (Appendix B, Appendix C, and Appendix D). I offered to have an informal chat with them to explain the project and my own positionality. Most participants were eager to do this.

Beyond an exercise in building rapport and explaining the project, these preliminary chats were part of my “continued commitment to move together as crips and comrades” (Mingus, 2010, para. 11). Like Price and Kerschbaum (2016), but in the context of different access needs, from

these very first communications with participants, I made explicit the crip and justice principles underlying my research and in the spirit of embodying the vulnerability of disclosure, I mentioned my own vulnerabilities and needs to my potential participants. Further, I underlined (to myself and to my participants) that we could work together to create the flexibility we needed.

During these chats, we discussed our experiences with mental health and disability, how we navigate queerness, academia, activism, and so much more. We talked about people we know in common and promised to build relationships and friendships. We talked about work we might do together in the future and planned to meet in person at a later date. On the days I didn't feel too well, or they didn't, these conversations took place from beds or couches. Defying the convention of an interviewer who withholds their own opinions on a matter so as to not influence potential participants, I shared my understandings of disability politics and beyond. I wanted them to know who they were entrusting their experience, their knowledge, and their stories to. There is an inherent power imbalance in the act of research interviews. Despite informed consent, participant checking of transcripts, and the right to withdrawal which aim to mitigate these imbalances, through this thesis, I have the final word on the content of these interviews. I am demanding an act of trust from my participants, and for me, it was only ethical that that demand be accompanied by an honest telling of my story, experience, understanding, and politics.

### **3.2.3 Navigating the interview process: format, topics, and building access**

The interviews themselves employed a combination of methods. The first part of the interview was influenced by feminist oral history methods. The narrative nature of a feminist oral history method allowed participants to provide an in-depth account of their activism from their perspective (Leavy, 2011). However, this needed to be balanced with my focus on specific aspects of the psychosocial disability movement. The second part of the interview, thus, used flexible semi-structured topic guides. The topic guides (one for activists with psychosocial disability and one for cross-disability activists) were developed using existing literature, blog posts, organisation websites, and informal conversations with activists in the field. Building on contextual information about the participant, the topic guides were tailored to focus on specific questions relevant to a participant's area of expertise.

In practice, I began each interview with an open-ended question asking about the participant's involvement in and understanding of psychosocial disability within their context. Despite providing all the participants with a broad list of topics I wished to cover in the interview, the



responses to this first question were very different. Some people gave me an account of their professional work. Some gave a short 5-minute answer with initial thoughts. Two interviews stand out for me. One where this first opener led to a 3-hour conversation about all the experiences that led them to their current work. Another where this question sparked an incredibly generative rant about the state of affairs within the psychosocial disability and disability movements. After this first response, in all cases, I followed up by picking up some aspects of their response and segueing us into the broad topics under the topic guide.

The interviews for both groups utilised prompts and probes to elicit information on topics specific to the participant such as participating in community programmes, UNCRPD and human rights activism, the role of knowledge production, involvement with the development agenda and/or mental health activism, and so on. The full topic guides with prompts are included in Appendix E.

My actual use of the topic guides within interviews was very fluid. As mentioned above, the distinctions I had drawn between psychosocial disability activists and cross-disability activists were less rigid than I had assumed and for several interviews, I borrowed from both topic guides. The topic guide and the questions I asked in interviews changed over the course of the project. I built on the insights and preliminary analysis from early interviews to probe into topics I had not anticipated. This, for me, highlighted the importance of starting my interview process with those on the outside of the mainstream movement and those I was least familiar with. As mentioned before, an interrogation of ‘activism’ and ‘activist’ became an explicit part of interviews. Other topics such as the UNCRPD became less prominent. I found myself borrowing phrases from previous interviews in future ones. Below is an excerpt from the end of an interview where we were talking about our wildest hopes for the future. It was only when I was checking the transcript that I realised that the phrase “this revolution, it’s not happening tomorrow” was used by a participant earlier. In this small way, not only was I in conversation with my participants, but through me, their ideas were also in conversation with each other.

**Akriti:** But it brings me to a question that I have no answers for. And I hope that you have some directions. Which is this...like, I’m not ending capitalism tomorrow.  
[chuckles]

**Sanya:** Sadly. [laughs]

**Akriti:** You know, this revolution, it’s not happening tomorrow. [laughs]

Most interviews were fluid and conversational, sometimes chaotic, and accommodated interruptions and tangents. The topic guide lay beside my laptop, reminding me of the topics I wanted to cover. Sometimes, I made little notes and scribbles as the interview proceeded, checking off topics as we covered them. Some interviews felt formal and structured, and I relied heavily on the topic guide as the conversation took a question-and-answer format. Other times and in other interviews, I barely looked at the topic guides, and the interviews resembled a version of collaborative knowledge generation, as both me and my interlocutor thought through the issues in real time. Sometimes, the tables were turned as participants quizzed me about my thoughts, unpicking them with follow-up questions as I tried to adjust to this role reversal.

**Akriti:** So, setting aside psychosocial disability, like is there use in a disability framing of mental health? Does that work at all?

**Renu Addlakha:** What do you, what do you think?

There were times when interviews came to abrupt ends when concentration and energy faded, to be picked up another day. I treasured these admissions, both mine and theirs, of fatigue and tiredness and the consequent sudden ends and pauses. They felt like what Mia Mingus (2011) calls “access intimacy”, an “eerie comfort” which characterises some interactions with “disabled and sick people who have an automatic understanding of access needs out of our shared similar lived experience” (para. 4-5). Access intimacy can be instinctual and organic, as it was in some cases; and in others, it was built and purposive. With every email and message, I had reminded my participants (and myself) that the research process should never come at the cost of *our* bodyminds and that it was okay to use WhatsApp instead of emails and/or have long gaps between contact. I now understand these messages as part of building that special form of intimacy.

Within the small number of interviews which felt stilted, formal, and more structured, I tried to respect the distance that some participants put between us. I adhered more closely to the topic guide in these interviews. The limits of building access intimacy based on ideas of shared experiences of madness and disability were starkly clear here. Sometimes our class, caste, gender locations made these experiences too far apart to bridge within the constraints of research interviewing.

There were other times when it was me who enforced that researcher/participant distinction and failed to create the collective access that is central to disability as method. There was at least one person I desperately wanted to include in my project and after almost a year, we managed to find

a time and date. It turned out that I was not feeling too well when that time arrived, but on that day, I put the research ahead of my needs. In another interview, a participant spoke about a person who was a key part of a very traumatic period of my life. I found myself beginning to dissociate and I should have ended the interview there. However, in that moment I could not get myself to express that vulnerability and kept pushing on despite being quite distressed. These moments of failure to embody and foreground disability principles in my research are all part of disability as methodology.

### 3.2.4 Afterlife of the interviews

The interview audio was recorded and then transcribed. Working as I was with limited energy, I relied on the university to provide me with extra funding to engage a transcription service. I chose Academic Audio Transcription<sup>31</sup>, a disabled-led organisation. The interviews were predominantly in English but often included sections in Hindi which I transcribed and translated myself. Keeping with both feminist and survivor praxis, I offered my participants the chance to review their transcripts and edit, clarify, and/or redact any part of the interview (Forbat & Henderson, 2005). Although most people did not respond to the transcripts, one participant made it clear that having the transcript was important to them:

there is so much with words going on, right? The language that we use, the finer details in the language, I'm very particular about certain words to be used and not used and stuff like that. So, the transcripts being available would be great after the interview. (RP)

Here too, I found a type of disabled camaraderie. It was not labelled as such but was an extension of crip time<sup>32</sup>. I apologetically told a participant that it would take me a while to get the transcript back to them because I needed to take some time off. It was them, at this moment, who reminded me that we must operate on whatever timeline our bodyminds want.

**RP:** Please take your time. I know about this time thing, so please do it whenever you can and send me. [chuckles] Yeah?

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<sup>31</sup> Academic Audio Transcription website: <https://academicaudiotranscription.com/>

<sup>32</sup> Crip time is a well-theorised concept. For Alison Kafer (2013), “crip time is flex time not just expanded but exploded; it requires reimagining our notions of what can and should happen in time or recognizing how expectations of “how long things take” are based on very particular minds and bodies. We can then understand the flexibility of crip time as being not only an accommodation to those who need “more” time but also, and perhaps especially, a challenge to normative and normalizing expectations of pace and scheduling. Rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds.” (p. 27)

**Akriti:** I will.

**RP:** This understanding of time has made me a very different person...I'm not in any hurry myself. Okay? So, I'm okay with time. As long as it'll happen, I'm fine with it. There's no hurry to do this...I'm good with however and whatever, because my page is also like that, you know? I had recently written on Facebook, "ASAP for me means as slowly as possible." [laughs]... whenever you can, yeah, send it.

Outside and beyond the interview, I have forged a different form of relationship with some of the participants. Sometimes, the conversation between a participant and myself continued right after, morphing both the relationship and the environment we had co-created to something different. More often, I continued to stay in touch with participants through messaging and emails, sending each other opportunities, event invitations, life updates, gossip, and memes.

### **3.3 Critical discourse analysis**

The interviews were not designed to reach a consensus or a unified common model of psychosocial disability activism. Rather, they were designed to elicit participants' multiple understandings of psychosocial disability and how they have used the concept within their work. The interviews, thus, aimed to trace the concept through different settings and to understand how it is informed by and informs these settings. Akin to a 'social life' approach, I wanted to understand "how, when, and where is the concept deployed?... Who enables that work and is in turn enabled by it? What new paths of power and channels of capital, financial and cultural, does it open up?" (Abu-Lughod, 2010, p. 32; Mills & Hilberg, 2019; Whyte et al., 2002). Questions such as these are questions of power, knowledge, and discourse. My research questions, asking how psychosocial disability came to be constituted and how it is mobilised and 'done' are also questions of power, knowledge, marginalisation, and resistance. To understand these questions, I used tools from Critical Discourse Analysis (CDA), using the interview transcripts as text. Drawing from critical social theory, CDA understands the text to be analysed as embedded within the historical, social, and political context. It focuses on how discourse (re)produces or resists inequality and injustice (Grue, 2011). It seeks to "speak to and, perhaps, intervene in, social or political issues, problems, and controversies in the world" (Gee, 2011, p. 9). It is thus an explicitly political approach which aligned well with my overall approach. CDA is often described as an "approach with a toolbox rather than a narrow school of research" (Grue, 2015a, p. 10). The flexibility of the approach as well as its utility in teasing apart the interplay of discourses, institutions, and power dynamics made it an appropriate mode of analysis for my thesis.

Before describing the steps I undertook for analysis, I want to expand on how I understand concepts related to discourses, knowledge production, and power and their relevance to my research, particularly how they connect to disability and epistemic justice.

### **3.3.1 Discourse analysis, disability, and interview texts**

Discourse analysis methods begin with the assumption that language is not neutral, but rather it produces and is produced through social and institutional practices (Wetherell et al., 2001).

Michel Foucault (1980) in his analyses posits that discourse, knowledge, and power are inextricably linked and that knowledge generation is both a product of power and the means through which it is maintained; and discourse lies at the heart of the power-knowledge nexus. Prior to the work of disability activists, medicalised discourses of disability (disability as deficit) were seen as common sense, i.e., they were naturalised and perceived not as discourses but reality (Hall, 2001). Through activism, advocacy, and research, disability actors troubled those assumptions bringing into being the social model of disability and denaturalising the discourse that disability is a matter for medicine (Blackmore & Hodgkins, 2012). Dominant discourses i.e., those which are highly visible, supported by actors and institutions framed as experts through other discursive formations, and hence receive more attention and resources, can be troubled by activist practices (Hall, 2001). Blackmore and Hodgkins (2012) frame the work of Disabled Persons Organisations (DPOs) as that which “can be read as resisting and countering disability oppression, as well as being part of the production of both emancipatory and disciplinary power” (p. 76). For psychosocial disability and mental (ill)health, dominant discourses continue to frame them as health issues (Cosgrove et al., 2019; Titchkosky & Aubrecht, 2015). The work of psychosocial disability activists and critical disability theorists trouble these dominant discourses and, in the process, create new ways of articulating and understanding disability and (ill)health (Grech, 2015; Meekosha, 2011; Mills & Davar, 2016; Mills & LeFrancois, 2018).

Furthermore, discourses play many functions in society. Foucault, in his work on madness and psychiatry, expands on how psychiatric discourse (and the medical and juridical institutions through which it operates) creates subjects—psychiatric ‘patients’ (Foucault et al., 2006). This process of subject formation as ‘patient’ limits the arenas within which the ‘patient’ has credibility. They create and maintain hierarchies: in our example, the differentiated power held by psychiatrists framed as experts and their objects of study, the ‘patients’ (Foucault et al., 2006). This is what Fricker (2007) refers to in her concept of epistemic injustice—the processes through which certain people are excluded from the realms of knowledge generation.

For many critical theorists, power is neither static, centrally located and nor does it flow unidirectionally (Foucault, 1980; Hall, 2001). Critically for my research, power in this understanding is not a totalising force but is inextricably linked to resistance and subversion (Blackmore & Hodgkins, 2012; Foucault, 1980; Swerdfager, 2016). Within this fabric of power-knowledge lie opportunities to subvert and resist oppressions, and language and discourses can provide a powerful way to do so. However, seemingly liberatory and emancipatory discourses constructed to challenge a dominant discourse are subject to institutions and other discourses which operate in the sphere. Power circulates “through a web of human social relations, connecting and engaging people as both the oppressed and the oppressor, the liberated and the liberator, the ethical and the unethical, the powerful and the powerless” (Blackmore & Hodgkins, 2012, p. 75). Understanding discourse and power in this way enables analyses of how potentially liberating discourses can also function as oppressive discourses. It allows us to look at what such discourses do, what they do not do, who they liberate, and who they exclude.

There are two aspects of discourse analysis within the context of my research that require particular attention: first, disability and discourse; and second, using discourse analysis to analyse interview transcripts.

Within disability studies and activism, a focus on discourse is contentious (Corker & French, 1999; Goodley et al., 2019). Many scholars have argued that the increased focus on the cultural and discursive aspects of disability has come at the expense of the materialist foundations of the social model of disability which was central to the mobilisation of disabled persons to improve the material realities of their lives (Jenks, 2019; Vehmas & Watson, 2013). Tom Shakespeare (2013) argues that the focus on discourse and representation can actually function to obscure the political and material concerns of the disability movement. As the previous chapter on theory and literature outlined, for me, disability is *both* materially and discursively produced (Corker & French, 1999). Analysing disability through a discourse lens includes analyses of the context within which disability is used and that this “usage-in-context has real political implications” (Grue, 2015a, p. 9). My analysis of psychosocial disability necessarily includes the ways material and institutional constraints shape, and are in turn shaped by, psychosocial disability as a concept. I therefore understand disability discourses as “not only mapped upon [disabled peoples’] bodies, lives and minds but also in the economic resources and regulations that govern their actual and potential actions” (Blackmore & Hodgkins, 2012, p. 84).

The use of interview transcripts as text for discourse analysis has generated debate and disagreement amongst researchers. Some argue that ‘naturalistic’ or ‘natural’ data such as

conversations, written reports, news interviews, speeches, and similar materials are better suited for discourse analysis and the ‘contrived’ nature of interviews is not as amenable to discourse analysis (Hammersley, 2014a, 2014b; Nikander, 2012). Martyn Hammersley (2014b) argues that research using interviews for discourse analysis must “adopt a strategy of deceit” and that given the differences between research paradigms and the ways in which people operate within their usual lives, “informants would probably have difficulty understanding the purpose of the research” (p. 538). Responses to this claim tend to focus on the argument that these problems are present in all forms of qualitative enquiry and that they can be somewhat mitigated by considering the research interview as a co-constructed interaction (Taylor & Smith, 2014).

These debates, while important, do not speak directly to my research. All the above positions neglect interview participants who themselves approach the topic at hand through a discursive lens. The people I chose to interview have specific expertise in psychosocial disability; they have purposively engaged in analytic processes themselves (whether they name it as such or not) to understand their experiences and identities within the context of institutional frameworks and discourses. The gap between the researcher lens and the participant lens, in this case, is not as large as imagined by Hammersley (2014b). It is equally important to note that my participants while experts, are not elites. Rather they are often marginalised within society and it is this marginalisation that give them the expertise to understand the interlinkages of power and knowledge (Mohanty, 2008). Finally, the rigid distinction between the researcher and the researched that the arguments above rely on is not as clear in the case of my research. I am part of, or at the very least an ally to, the psychosocial disability movement in India. The information I provided to my participants before the interviews makes clear my relationship to the movement. A significant part of that information was how I see this project’s alignment, or lack thereof, with the broader movement.

### **3.3.2 The process of analysis: ‘Doing’ CDA**

Like the rest of my project, my analysis process was iterative. My first step was to read and re-read the transcripts. Using paper, pen, highlighters, and flags, I went over the transcripts several times, making notes as I went along. These notations connected different parts of a transcript, connected the text of the transcript to literature and concepts, and finally connected the transcripts to each other. I marked out parts that surprised, things that confused me, and allowed myself a certain degree of stream of consciousness in my notations. I did this concurrently with data collection, going back to older transcripts as new interviews brought up new questions and

ideas. I systematised these initial thoughts on each transcript and on the corpus as a whole using Word documents.

I then undertook a reflexive thematic analysis in service of the discourse analysis in order to provide a provisional ‘map’ of the key themes and areas being engaged. A reflexive thematic analysis, as the name suggests, emphasises researcher reflexivity and the context of researcher-participant dynamics in addition to allowing theoretical flexibility (Braun & Clarke, 2019; Terry & Hayfield, 2020). The thematic analysis served an organisational purpose as the first step. Many of the broader themes of my chapters came through this process—psychosocial disability beyond category; psychiatry’s enduring presence; the schisms between the law and life; the centrality of funding ecosystems; dreaming; the everyday.

Finally, I constructed questions to put to the text through my engagement with understandings of the concepts of knowledge, power, and discourse outlined above as well as with CDA to guide a deeper analysis of the transcripts.

1. When and how is the word psychosocial used? What follows the word? What alternate terms could have been used? Which discourses could have been leveraged?
2. When talking about psychosocial disability, what is being foregrounded and what is backgrounded? What alternate meanings are ignored? What is left out? How do these connect with other relevant discourses?
3. What institutional and material factors impact how participants talk about psychosocial disability? Preceding and following different usages of the term, what are the material and institutional factors (such as legislation, socio-economic factors, healthcare institutions) that participants refer to?
4. What practices and actions are made possible by using psychosocial disability frameworks/identities? What practices and actions are hindered? What actions and practices are seen as within the scope and what is excluded?
5. What ways of coming together and organising are foregrounded, and which are left out? What alternate ways of organising are discarded?
6. How is power exercised within psychosocial disability activism, by whom, and for what purposes? What are the ways participants explicitly refer to power, marginalisation, exclusion, privilege, and resistance? How do participants position different actors within the psychosocial disability activism? What are the pathways of activism which are made possible by these relational positionalities? What are hindered?



An overall structure of my analysis emerged through this process—understandings of psychosocial disability; navigating institutions and discourses; coming together as a movement; and activism in the everyday. I used different tools and focussed on different questions to get a deeper analysis of each of these sections. After writing the empirical chapters, I drew a visual representation of the concepts and themes which emerged from my analysis and form the foundation of my central arguments. This is presented at the end of this chapter.

The reflexive thematic analysis yielded some aspects of the understandings of psychosocial disability—the various usages of psychosocial disability as a term; the ways in which participants came to use psychosocial disability as an identity; the boundaries of the term; and the ways in which participants use psychosocial disability beyond identity and category. Using the first analysis question as a guide, I highlighted each articulation of the word ‘psychosocial’ in a transcript. I then paid attention to the word that followed it or preceded it. Next, I expanded my focus to the surrounding sentence and paragraph. I repeated this process for each transcript. This yielded a list of arrangements of the terminology. I then turned my attention to how participants described their relationship to psychosocial disability, what purposes it served for them, and its relationship to other identities and discourses. I also analysed the boundaries of psychosocial disability as described and/or implied by my participants. I paid close attention to the institutions that participants referred to in relation to these questions as well as those they discarded or excluded. This, along with the positionalities of my participants themselves, is the critical context within which my analysis is framed. This part of my analysis is represented in Chapter Four.

The second empirical chapter, Chapter Five, speaks to my larger question on how psychosocial disability is mobilised and ‘done’. The reflexive thematic analysis yielded two main higher-level spheres of action—personal, collective, and professional interactions with psychiatry as well as engagement with the state, legal mechanisms, and human rights discourses. Within these spheres, I concerned myself with the actions participants take and understand as psychosocial disability work, and how these actions are supported by and support particular discourses. Towards this end, I focussed my analysis on questions such as: What are the material and institutional factors (such as legislation, socio-economic factors, healthcare institutions) that participants refer to? What practices and actions are made possible by using psychosocial disability frameworks/identities? What practices and actions are hindered? What actions and practices are seen as within the scope and what is excluded?

The third empirical chapter turns towards examining how the psychosocial disability movement itself is organised. Through analysis of the transcripts, I mapped the various actors that occupy the psychosocial disability movement, their relationships to each other, the structures they create and are constrained by, and how power circulates within it. I honed my analysis using the following questions: What ways of coming together and organising are foregrounded, and which are left out? What alternate ways of organising are discarded? How is power exercised within psychosocial disability activism/movement, by whom, and for what purposes? What are the ways participants explicitly refer to power, marginalisation, exclusion, privilege, and resistance? How do participants position different actors within the psychosocial disability activism/movement? What are the pathways of activism which are made possible by these relational positionalities? What are hindered? This is reported in Chapter Six.

The final section of my analysis—crip utopias and activism in the everyday—was the most difficult to unpack. It seemed at first, and in some ways continues to be, somewhat disjointed and drawing on too many concepts, ideas, and actions. It asks and partially answers the questions—what possibilities of resistance exist within and outside of overlapping overwhelming constraints? What arrangements of ideas, dreams, and organising are experimented with? How are these actions related to concepts, theories, histories of resistance? This is reported in Chapter Seven, the final empirical chapter.

It was critical to me that my research remain open and evolving. Following from feminist disability studies, it “asks difficult questions but accepts provisional answers,” privileging “the partial, the provisional, the particular” (Garland-Thomson, 2011, p. 40).

### **3.4 Ethics and positionality in practice**

Questions of ethics and positionality are at the forefront of every research project. These were amplified for this project, where the dividing lines between my work as a researcher and my work as an activist were blurred at best, where some of my research participants were also my comrades, colleagues, and friends, and where the tensions between academic obligations and an activist ethos were ever present. I borrowed concepts, ideas, and practices from feminist scholars, disability theorists, and social movement researchers to navigate these tensions ways which enabled me to examine my positionality without centring it. In addition to submitting an ethics form to the London School of Economics and Political Science Research Ethics Committee (LSE REC), I understood the questions it raised—of vulnerability, of payment and reciprocation, and of naming and representation—as continuously evolving. This section focuses on my ethical practice—both procedural as well as the subtle, murky, situational, and everyday

ethics of research—and reflects upon the shifting positionalities between me and my interlocutors (Guillemin & Gilliam, 2004).

### **3.4.1 Procedural ethics: vulnerability, payment, and anonymisation**

I received official ethics approval for my project from the London School of Economics and Political Science (LSE). I did not seek ethics approval from India. There are limited institutions which can provide ethics review for social science projects in India. Most, if not all, national ethics boards are concerned with clinical trials and other forms of medical research. The primary option available to me would have been to collaborate with a university and seek ethical approval through their system and process. However, the increased political interference in university affairs and the deliberate targeting of researchers and academics engaged in “anti-national” research<sup>33</sup> made this a risky proposition that would have increased my vulnerability. Instead of reframing my research so as to appear more benign, i.e., not critical of any state action, I decided to not seek ethics approval from an Indian institution.

I submitted an ethics review request including details of my fieldwork plans as well as data management strategy to the LSE Research Ethics Committee. The REC approved the project. Although the process of approval was smooth, there are some ethical questions which I believe need elaboration here.

#### *Vulnerability*

‘Vulnerability’ in both formal ethics reviews and explorations of subtle ethics is framed as located within the research participant (Leahy, 2022). A common stumbling block for many survivor researchers is a blanket framing of those with mental health issues as ‘vulnerable’. Within this framing, my research participants, as people with psychosocial disabilities, would be classed as vulnerable. However, such a rigid understanding of vulnerability neither reflects their standing as experts and activists nor does it accommodate principles of disability justice and research (Bracken-Roche et al., 2016; Hasbrouck, 2021). For me, vulnerability is “a dynamic, relational property describing an asymmetry between participants and those involved in the

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<sup>33</sup> Universities in India are increasingly a significant site of governmental interference and fascist violence. There has been widespread criminalisation of student protests, administrative complicity in police brutality on university campuses, imprisonment of academics working on ‘political’ or anti-national issues, and political appointments of university leadership. Furthermore, Indian universities have received an advisory of what topics can be taught and researched and any event with international attendees in-person or online requires governmental approval. As is the case often, the university has become increasingly censored and unsafe. For more refer to Das (2024), Roy (2020), and Vijayan & Rechia (2023).

implementation and conduct of research that can be rendered more or less significant by situational factors” (Bracken-Roche et al., 2016, p. 337). Vulnerability in this framing is not “an intrinsic property of the participant” but similar to disability, it is produced through inequality and injustice and hence can be mitigated by addressing those factors.

There was of course the possibility of moments of vulnerability and distress within the interviews. I trusted my interviewees to assess their own ability or desire to continue, pause, or stop the interview. My opening question was a broad one, enabling participants to set the tone and content of the interview. I followed their lead and steered away from personal experiences of distress and trauma unless they brought them up first. I frequently reminded them that we could talk about what they wanted to focus on and that they need not answer every question. Finally, I followed Price and Kerschbaum (2016) in their reflection on employing crip methodologies and exploring their own vulnerabilities as disabled researchers working within contexts which normalise able-bodiedness. I have attempted to follow in their example by acknowledging and recognising my own vulnerabilities as well as those of my research participants, but I did not assume that my participants were by definition ‘vulnerable’.

### *Payment*

I offered all participants a payment of GBP 30 for the interview. Payment to participants beyond incidentals (such as travel costs and food) is increasingly debated within qualitative research (Gelinis et al., 2018; Head, 2009; Warnock et al., 2022). The arguments against payment include that it increased the potential for bias by making participants feel compelled to provide the answers they think the researcher is looking for, that payments are solely used by researchers to encourage and/or increase participation, and that payment in and of itself can nullify informed consent (Head, 2009). In reading this literature, I found a repeated undercurrent of suspicion towards both researchers who offer payment and research participants who accept it. I do not argue that payment to research participants is entirely unproblematic; certainly, the dire poverty that many folks live in can and does raise ethical questions about coercion. But for me, as for Goodman et al. (2004), “it seems obvious that [research participants] should be compensated for their time, especially since the researchers themselves are likely compensated.” (p. 821). If I say, as I do, that my participants are generating knowledge through their work, that I aspire to be non-extractive (as far as possible) in my research process, and that I hope to embody disability justice politics, not offering compensation to my participants for their time, knowledge, and generosity would be unethical. As I myself know, people with psychosocial disabilities are often asked to share their stories, experiences, and knowledge at conferences, in research consultation

committees, in Diversity and Inclusion initiatives, without any thought given to remuneration. It is exploitative, extractive, and feels incredibly frustrating. I was able to make this case to the LSE REC and was given approval to provide compensation to my participants. The purpose of the payment i.e., to compensate for participants' time and work, was explicitly stated in the information sheet, and reinforced during preliminary chats and/or the interview itself. Any concerns about bias, undue influence, were not borne out. Several participants declined the payment, choosing instead to pass it on the next participant.

### *Anonymisation*

Within the consent form, I offered my participants three choices regarding anonymity—first, to be fully anonymised; second, to be fully identified; and third, to decide after reviewing the transcript. For some participants, it was important that their names were attached to their ideas and work. I too wanted their contributions and role in disability activism to be recognised and in accordance with their wishes, they are fully identified using their full names in the thesis. Others, especially those who are new in their engagement with the movement, chose to be anonymised. Finally, some participants who indicated that they would inform me of their anonymity choices after reviewing the transcripts never did. In these cases, I made the decision to anonymise them. Given the small size of the field of psychosocial disability activism in India and the specific vulnerabilities of my interlocutors, I constantly had to find the balance between providing information about my interlocutors to contextualise their words and ensuring their anonymity. I have tried to err on the side of protecting their anonymity.

A key and continuing question for me was what markers to use for those who have chosen to be anonymous. Some researchers use pseudonyms, others use numbers, or a descriptor followed by a number (Heaton, 2022). Each of these options presented problems for me. Using numbers instead of other options felt wrong, as if I was somehow taking away their humanity and expertise. A second option would have been a descriptor followed by a number. For instance, *psychosocial disability activist 04* or *psychosocial disability writer 07* or *Dalit disability activist 06*, depending on how they identified themselves within the interview. For those who did not vocalise a clear preference, I would have used *psychosocial disability actor*. The third option would be to use pseudonyms which while increasing readability posed other challenges. How to choose the pseudonyms? Names in the Indian context are also markers of religious, regional, and caste locations. For instance, if I am referring to a Muslim psychosocial disability activist, I could give them a name which either marks them as Muslim or marks them as another religion. Given how small the field of psychosocial disability is, giving them another name but still marking them as a

Muslim activist does not go far enough in anonymising them and risks that they might be identified by those who know the field. On the other hand, if I were to give them a name that obscures their religious identity, I am also obscuring a key part of their identity which in the context of this project, is also a key part of their work.

I excluded the first option—using numbers—early in the process but continued to vacillate between descriptors with numbers and pseudonyms until late in the process. I wrote the initial drafts using descriptors with numbers but reading it back, the text felt impersonal and reminded me of reading psychiatric notes with case numbers. In the end I chose to use the full names of people who chose to be identified and pseudonyms for those who wished to be anonymous.

Picking pseudonyms was a long process and I took several steps to mitigate the issues I had identified. I generated a list of names, some of them gender neutral, some of them used by Hindu, Muslim, *and* Christian communities, some used in multiple regions. I then tested the names with a close group of friends familiar with the Indian context as well as generative AI, asking them to give me a list of caste, class, religion, gender, and regional characteristics they associate with the name. My aim was that each participant would be assigned a pseudonym which aligned with their social, gender, and religious location but was not exclusive to it. For instance, a Muslim participant received a name used by Muslim communities but also used by other religious communities, hence balancing the need to honour their location while also maintaining anonymity. One participant prefers only to use their initials. In addition to changing their initials, I have also used initials to refer to several other participants to further muddy the waters. I checked with all participants if they were comfortable with their assigned pseudonyms and gave them the option to choose alternate ones.

### **3.4.2 Considering positionality: Interlocutors, friends, comrades?**

Like my research participants, through the course of this PhD and outside of it, I navigate multiple positionalities—a researcher, a student, a disabled person, a mad person, an activist, a person of colour, a Savarna person, and a queer ciswoman. These positionalities as well as my experiences of mental (ill)health and mental health systems are inextricably linked to this research process and to everything else I do. Within the context of research interviews, I shared some identities and experiences with my participants, and more importantly I also shared political positions and a common project with them. But I am also removed from them as a researcher occupying particular social and political locations and based at a university in the global North. The interviews were fluid engagements where I responded as a disabled person asking for a break or explaining why I am conducting an interview from my bed; a comrade as I listened and

extended solidarity when participants described their encounters with institutions and their dreams of change; and a researcher when I asked probing questions. This fluidity also shapes how the empirical chapters are written. I name these positionalities to remind myself that the power imbalances within this project are ever fluctuating, and working and writing reflexively is a continuous project and process. I aspired to practice an ‘uncomfortable reflexivity’ which beyond a methodological tool is about “whether we can be accountable to people’s struggles for self-representation and self-determination” (Visweswaran cited in Pillow, 2003, p. 193). Within the context of this thesis, this means that I examined my positionality, without centring it, throughout the research process including formulating the research questions, outlining theoretical principles and methodology, analysing how participants position me within interviews, and writing transparently and reflexively, and finally, being ever be mindful of the foundational aim of this project i.e., to contribute to the psychosocial disability movement.

I call the people I interviewed within this thesis interviewees, participants, and/or interlocutors. While referring to the same cohort of people I interviewed, and sometimes variedly referring to the same person, they are not used as synonyms. For me, ‘interviewees’ is the word I default to when discussing someone I interviewed. It is, as much as a word can be, the most neutral option. For most of the interviews, despite a friendly conversational crip-friendly atmosphere, people I interviewed felt very much like participants. I asked most of the questions, and they gave most of the answers. There was a small, but not insignificant, portion of interviews where the already blurred boundaries began to dissolve. Conversation moved effortlessly, I put the topic guide aside, I gave long responses about my thoughts on the matter, my body and tone reflected the ease of our engagements. In the following chapters, I often use the word interlocutor to represent these portions of the interviews.

As I have mentioned before, I want to see my work as an extension of the psychosocial disability movement in India. I share a lot with my participants—experiences of psychiatry, disappointments with the shape of the movement, concern about the current political situation in India, cultural references like films and songs. At the same time, I am apart from them—I am based at a university in the global North which requires a certain amount of social and material capital. As such, I am both an insider and an outsider, or what some scholars have called, an inbetweenner (Acker, 2001). Feminist theorists, survivor researchers, social movement scholars, and disability theorists, amongst others provide ways to navigate this positionality (Acker, 2001; Essien, 2007; Faulkner, 2004; Gillan & Pickerall, 2015).

Insider-ness and outsider-ness concern not only how I see myself. Equally, or more importantly, it is about how my participants see me. As I was doing the interviews, I noticed that I very much wanted my participants to like me and see me as an insider. In part, I know that this was because, just like them, I too yearn for community and belonging. I wanted this amazing community of people to see me as a part of it and as one of them.

However, there are particular complexities that arise from being from the global South, in the global North, and doing research on/with the global South. Where I am from and what I am of is a liminal space (Martin & Dandekar, 2022). In the field of psychosocial disability activism, where the North/South divide is central to movement politics, these contestations were projected upon me. For almost all of my interviews, I attempted to somehow legitimise my standing as being from the global South by displaying my Indian-ness by wearing a kurta or a dupatta. It is an embarrassing admission but a telling one. I did not do this consciously or with that explicit purpose, I just did it out of instinct. For me, this underlines the point that reflexivity and positionality are embodied and visceral.

A key part of research is concerned with the authors of a story, their positionality, and their experiences, i.e., who tells a story and who creates knowledge. This is reflected in my intentional choices about the social and political locations of who I chose to interview, and equally in the absences and gaps, i.e., those I did not include or interview. These included people who were left out because of my framing of the research, those who refused to be part of the project, as well as the people and knowledges I refused to include.

My interlocutors hail from a wide range of backgrounds—some of them growing up with the kinds of intergenerational economic deprivations that intersect with religious and caste backgrounds; some have faced or have loved ones lost to state and fascist violence; some grew up in far-flung rural areas of the country. Their actions are shaped by their experiences and their political commitments. They wear many hats in their day-to-day life. For instance, one participant works at a small disability organisation but spends every evening working on community organising and political education within their neighbourhood. Despite this diversity, there are several worlds which remain missing from this thesis because it uses psychosocial disability as a departure point. As the next chapter will explore in detail, it is an English language word which circulates in limited realms. Many people, communities, and activists cannot or decide not to engage these realms. They certainly theorise and action political understandings of mental (ill)health and disability but do so without using the language of psychosocial disability, or even madness or mental (ill)health. The absence of their knowledges from this thesis means that



it is limited in its ability to claim insights into all marginal ways of understanding mental distress from a political and structural perspective. While the diversity of experiences that my interlocutors bring enabled me to critique what psychosocial disability currently means; a different starting point would have provided critiques of the concept in its entirety in any of its forms and enabled access to different types of political understandings of disability and madness. Similarly, if my focus had been a broad array of cross-disability activists, different means of knowledge production such as those by activists with intellectual disabilities could have been highlighted.

There were people I reached out for potential interviews who, either through an explicit decline or by not responding at all, refused to be part of it. Amongst them, there were some who were busy or dealing with life and did not want to add the burden of a research interview to their plates. People who refused to speak with me as part of the research project for political reasons were almost always those from Dalit Bahujan Adivasi communities and movements. I am a Savarna researcher with no background in anti-caste movements, an outsider at best, an oppressor at worst. Despite all claims and aspirations for this research to be part of or at the very least useful for the activism I study, it is also part of an ugly tradition of the “academy’s voracious hunger for secrets” (Tuck & Yang, 2014a, p. 233). Elsewhere, Tuck and Yang (2014b) write that “refusal is not just a no, but is a generative, analytic practice” and “turns the gaze back upon power” (p. 817). In this case, refusal reveals the limits of disability kinship, my real and perceived complicity with the colonial academy, the layers of caste and class privilege that enabled my entry into the academy, and the ugly history and experience of research within marginalised communities (Smith, 1999).

Refusal<sup>34</sup> on my part as the researcher is equally worthy of examination. First, there were some people I refused to interview—I knew them to be bullies and I did not wish to give them a platform. Second, refusal is also about where and how something is told. Things my participants told me once the recording was off or in the preliminary chat were not told for the purpose of research—they were important for my participants to share with me but not share with the people who will consume my thesis. Third, there are parts of interviews, and of myself, that I have chosen to withhold from the reader. For instance, I have chosen to leave out some of the strategies my participants use to evade state surveillance and violence from this thesis. This is important knowledge, and it is knowledge I will disseminate and pass on orally, but in my

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<sup>34</sup> I term it refusal because my decisions came within the context of a certain set of unstated expectations and demands (for instance, approaching prominent and influential participants) which I refused to abide by.

estimation, it is unsafe to write and publish. Finally, refusal for me in this project is a continual practice of denying the urge to tell a singular linear story. hooks (1990) critiques the compulsion of the privileged to ask those on the margins to “only speak from that space in the margin that is a sign of deprivation, a wound, an unfulfilled longing...[to] only speak your pain” and not “in a voice of resistance” (p. 243). In this thesis, I did not elicit and have not provided in my writing detailed accounts/proofs of my interlocutors’ marginality. Rather, following hooks, I have attempted to refuse that compulsion and to write about both the oppressive nature of structural violence but equally about the ways of resistance.

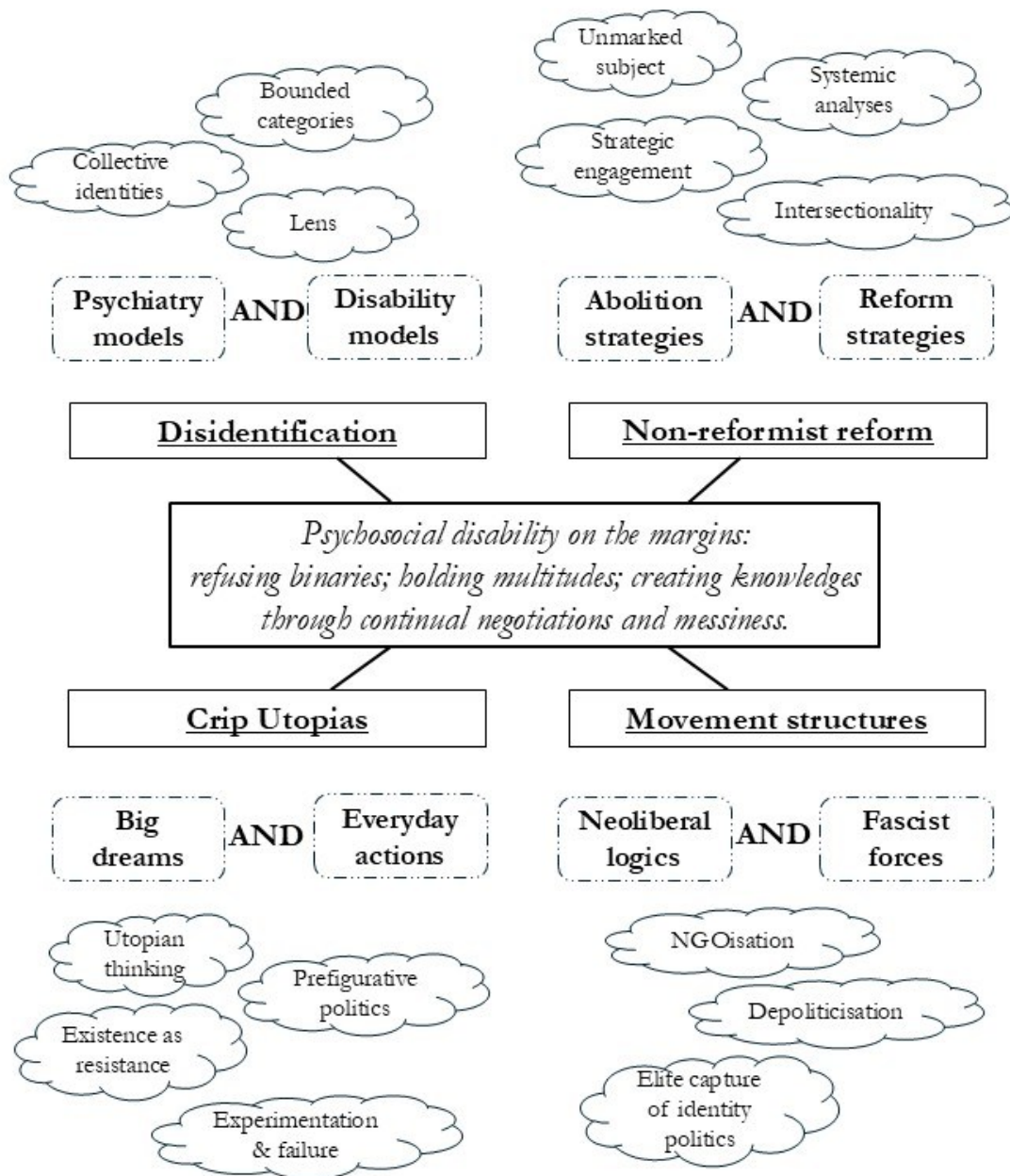
In conclusion, I have grappled with many questions about my relationship to my research topic, my relationship to my interlocutors, and to the broader psychosocial disability movement. I have attempted to navigate the tensions described in this chapter by adopting a reflexive and ethical practice. In the words of a close friend and fellow academic, for her and for me, this entails:

asking again and again, 100 times a day, of yourself: is there ways I can lessen/address/be transparent about questions of ethics and how you navigate that? So, accounting for yourself and the stories you tell in ways that readers can figure out your political investments. Asking yourself again and again - whose side are you on? The side of power or the side of resistance? (Pandit, 2023, n.p.)

### **3.4 Conclusion**

Methodology, for me, is an act of explicit political practice. The methods I describe, like all methods, “are not neutral devices” (Hine, 2005, p. 7). This chapter provided an accounting of what, why, and how I did this research. In the very first section of this chapter, I stated that disability as method places “disability in conversation with other concepts and worlds” (Friedner & Weingarten, 2019, p. 485). Through my descriptions and analyses of encounters within the research, I attempted to show what that looks like in practice. I interviewed 25 psychosocial and cross-disability activists about their work and analysed their interviews using critical discourse analysis. And through describing that process, I also expanded on academic ableism and its demands; shifting marginalities and positionalities; the relationship between academia and other knowledge generation spheres and the ensuing relationships between the people who occupy them; and on the limits of any one identity or positionality to shape and/or explain our work. Ultimately for me, disability as method is a refusal to yield to neat categories and tidy stories. It does not progress linearly, it is dependent on both excessive planning and entirely adaptive, it does not shy away from failures and refusals, and it is honest and transparent about all the tensions and contradictions that surround research.

## Visual representation of findings and concepts



## Image description

The image primarily consists of boxes and clouds with text within them. There is a repeated pattern in each quadrant—an underlined text within a box connected to a big central box; two smaller text boxes connected by the word “and”; and clouds containing text near them.

At the centre of the image is a box with the text “Psychosocial disability on the margins: refusing binaries; holding multitudes; creating knowledge through continual negotiations and messiness”. There are four lines emerging from the box.

In the top left quadrant, the central box leads to a box with the text “Disidentification” which is underlined and bolded. Above this, are two smaller boxes connected by the word “and” which is emphasised. The text reads “Psychiatric models” ***and*** “Disability models”. Above the two boxes are three closely clustered clouds, each reading “collective identities”; “bounded categories”; “lens” respectively.

In the top right quadrant, the central box leads to a box with the text “Non-reformist reform” which is underlined and bolded. Above this, are two smaller boxes connected by the word “and” which is emphasised. The text reads “Abolition strategies” ***and*** “Reform strategies”. Above the two boxes are four closely clustered clouds, each reading “strategic engagement”; “systemic analyses”; “unmarked subject”; “intersectionality” respectively.

In the bottom right quadrant, the central box leads to a box with the text “Movement structures” which is underlined and bolded. Below this, are two smaller boxes connected by the word “and” which is emphasised. The text reads “Neoliberal logics” ***and*** “Fascist forces”. Below these two boxes are three closely clustered clouds, each reading “elite capture of identity politics”; “Depoliticisation”; “NGOisation” respectively.

In the bottom left quadrant, the central box leads to a box with the text “Crip utopias” which is underlined and bolded. Below this, are two smaller boxes connected by the word “and” which is emphasised. The text reads “Big dreams” ***and*** “Everyday actions”. Below the two boxes are four closely clustered clouds, each reading “utopian thinking”; “existence is resistance”; “experimentation and failure”; “prefigurative politics” respectively.

*Interlude*

Onyx: *Being called back to my body but not in*

*a casket or a tomb or a shell...*

*A home. A temple. A sanctuary.*

*I take a moment to just...breathe...*

*and feel the heaviness leave*

*and I release myself from the versions*

*of me you created to survive your fear*

Sable: *I release myself from the versions*

*of me I created to stay alive.*

*(Cameron, 2024, p. 54)*

#### **IV. No singular meaning: crafting a dynamic psychosocial disability to understand ourselves and the world**

Terminologies do matter, because language matters. And language does communicate our understanding of how we understand certain phenomenon, and what are the frameworks or practices or disciplines which inform that understanding, and which inform our interventions or our practices on the ground when we're dealing with such phenomenon. So, in that sense, terminology does matter, language does matter. (*Harsha*)

As the quote above exemplifies, language and terminology can enable or hinder activist actions; they change the realms of possibilities in our understanding of an experience, an issue, and the practices that follow. This chapter, hence, focuses on how the term psychosocial disability is used by my participants. I conducted a critical discourse analysis to examine the usage of "psychosocial disability" across four dimensions: the usage of the term at the level of the text; the contestations around the boundaries of psychosocial disability; the journey participants described towards adopting it as an identity; and finally, novel ways of understanding what psychosocial disability is and what it can do for activists.

All participants referred to the changing language and “new words” (*Ambika*) that have emerged around mental (ill)health. Some participants attribute this to the need to find new ways of understanding mental distress. They posit that the constantly changing landscape emerges from people's attempts to understand their own experiences and mobilise against existing oppressive or ill-fitting frameworks. However, one participant put forth another reason with a hint of derision:

*humaara system hain, ki hum log jo karte hain, psychosocial disability hum log international standards ke hisaab se term change karte rehte hain, har do saal pe* [the system we have within our psychosocial disability work is that we keep changing the term according to international standards every two years]. (*Abhishek Anicca*)

*Abhishek Anicca* understands this changing language as that which is imposed top-down, from international bodies such as the WHO and the UN as well as academia. A consequence of ever evolving terminology is that there is no consensus on what terms to use to understand one's own experience and to guide one's activist actions. “Mentally ill”, “mad”, “neurodivergent”, “person with lived experience” are amongst some of the terms that came up repeatedly, each one understood in different ways according to the positionality of the person using the term. I am underscoring this diversity at the beginning of the chapter to, first, explain the need to

deconstruct the term psychosocial disability on its own terms and in relation to other terms and second, to highlight that none of the debates surrounding these terms are settled.

This chapter answers my first research question: how is psychosocial disability constituted and understood by psychosocial disability activists in India? Previous literature has focused on two understandings of psychosocial disability. First, it has traced the emergence of psychosocial disability as a liberatory collective identity (Davar, 2013). Second and to a lesser extent, scholars have attempted to clarify the boundaries of psychosocial disability as a disability category (Addlakha, 2015; Plumb, 2011). The literature highlights that psychosocial disability as an identity enables us to look beyond biomedical causes of and interventions for mental distress, emphasising the social model of disability, i.e., a focus on the social structures which create psychosocial disability (Davar, 2013). My findings add much-needed complexity to this conclusion. For my participants, psychosocial disability is neither an outright rejection of biomedical and psychiatric understandings of disability nor a wholesale acceptance of the prevailing social model of disability. Rather, a psychosocial disability identity is formed with and maintained through continued negotiations with both psychiatry and disability. It involves bodies, emotions, and social structures concurrently. As a category, my analysis shows that the elements that are emphasised when drawing the boundaries of psychosocial disability are embedded within the institutional and cultural understanding of disability, i.e., questions of who is or isn't psychosocially disabled are a result of the legacy of medical categorisation within disability legislation, cultural legitimisation of some forms and expressions of distress, access to material benefits and welfare, as well as desire for finding community. It is a result of, and results in, practices of gatekeeping which in turn reflects the broader influence of neoliberalisation of policy as well as an internalised ethos of competition.

My analysis shows that understandings of psychosocial disability are formed in community with other people, texts, ideas, and practices. For my interlocutors, mainstream understandings of psychosocial disability as an identity and category lead to tensions and debates—the place of the body, who counts as disabled, the utility or lack thereof of psychiatry, the limits of social models of disability to reflect diverse experiences and create change. However, these tensions are also generative and lead to a different understanding—psychosocial disability as a lens. This framing emerges as a result of my interlocutors navigating different elements of their identity and experience—Dalit, queer, Muslim, disabled amongst other. Mainstream framings of psychosocial disability do not capture their experiences or their activist aims. For my interlocutors, psychosocial disability must incorporate the embodied, the structural, and the emotional aspects of the experience of multiple marginalisation. Importantly, they do dismiss any particular

formulation of mental (ill)health or disability in its entirety; rather they continually engage in analyses of psychosocial disability in community and negotiation with others.

I argue that my interlocutors use different aspects of the prevailing models of mental (ill)health and disability and through a process of disidentification form and re-form psychosocial disability as a radical lens that can hold together counter-posed forces and contradictory ideas. In this way, psychosocial disability is a dynamic site of continuous negotiation and holds within it the capacity to do many different things. I rely on José Esteban Muñoz's (1999) concept of disidentification which is "a third mode of dealing with dominant ideology, that neither opts to assimilate within such a structure nor strictly opposes it; rather, disidentification is a strategy that works on and against dominant ideologies" (p. 11). This mode of engagement is neither an identification with nor a counter-identification against an ideology; rather disidentification is when minoritarian subjects take aspects of the dominant ideology and reformulate them for their own purposes. Although Muñoz was theorising disidentification within the context of queers of colour set against white heteronormativity, Sami Schalk (2013) uses the concept to describe her relationship as a black fat queer woman to the predominantly white disability studies field. I argue that while the literature has represented psychosocial disability as a process of rejecting and/or opposing psychiatric formations of self and concurrently as a desire for assimilation into disability frameworks, my interlocutors whose understandings of self and the world are intersectional, come to understand psychosocial disability through a process of disidentification with *both* psychiatry and disability.

The first section of this chapter focuses on the ways in which "psychosocial" and "disability" are employed by my participants concluding that while the choices and arrangements of certain terminologies are important, the person's relationship to mental health and disability is equally important in determining the meaning and significance of that terminology. This section also serves to unpack the landscape within which my interlocutors are using the term psychosocial disability and set up the debates and issues which future chapters examine in detail, and as such is written more narratively. The second section focuses on psychosocial disability as a bounded category and locates that understanding firmly within medico-legal institutions. The third section explores the changing and complex relationship my participants have to mental health and disability structures and concepts. It highlights how and why they came to psychosocial disability identities and what links they retain to other settings they have traversed. The fourth section foregrounds a new radical way of thinking—psychosocial disability as a lens. I conclude that my interlocutors are searching for ways to employ psychosocial disability which can accommodate a multitude of issues and experiences. Psychosocial disability as a lens is less concerned with who



counts or does not count as psychosocially disabled, or who can or cannot adopt a psychosocial disability identity, but rather on how psychosocial disability can be used to understand, unpack, and change conditions of injustice and inequality as well as identify and challenge the structures which support them.

#### **4.1 What even is psychosocial disability?**

I set out to understand psychosocial disability in this project, and I discovered participants using the term in a myriad of ways. Predictably, participants used the term “psychosocial disability” in lieu of mental illness, mental disorder, and psychiatric diagnosis, i.e., to distance themselves and their understanding of mental (ill)health from psychiatric and biomedical discourses. An initial reading of the literature and these interviews might suggest that the term psychosocial disability does the work of both locating the problem outside of the individual (psychosocial) and outside the sole realm of psychiatry and medicine (disability), as is generally argued (Human Rights Watch, 2020; United Nations Committee on the Rights of Persons with Disabilities, 2007; World Health Organisation, 2022). However, to fully understand how the term is understood, and in some ways being constructed, by activists, we need to break it down. Towards this end, I first look at the word “psychosocial” and how it is used, followed by a similar analysis of the word “disability”, and finally bring those together by looking at the contexts within which these words are used. This section adds to the existing literature on how psychosocial disability is understood by presenting findings which show—one, psychosocial disability does not entirely disregard the bodymind in favour of social structures within the experience of disability, but rather it can and does hold room for the interrelationship between social structures and the bodymind; two, the experience of multiply-marginalised psychosocially disabled persons enables a political reading of disability; and three, understandings of psychosocial disability are not immutable but rather, shift depending on who is utilising them and in what context. For my interlocutors, an emphasis on social factors does not negate the role of the body. Rather, the term psychosocial highlights the intricate connection between social structures and the bodymind. While the social model of disability is a valuable starting point, it does not capture that the bodyminds of those who are multiple marginalised are sites of structural discrimination and violence, and as such their impairments are not neutral. Ultimately for my interlocutors, no word or term can be separated from power relationships and positionalities, and they continually raise questions about who and what purposes these concepts serve.

#### 4.1.1 Understanding “psychosocial”

My search for words used in combination with “psychosocial” in the interviews yielded a broad range of arrangements—psychosocial distress and psychosocial crisis; psychosocial factors and psychosocial lived realities; psychosocial aspects and psychosocial understanding; amongst others. This sub-section argues that “psychosocial” can offer a more nuanced approach than what is implied by the literature. It doesn't simply shift focus away from medicalisation and the bodymind towards purely social explanations of distress; instead, it puts the two in conversation with each other. For my interlocutors, this is particularly crucial when examining multiple marginalisation. For example, queer people often face violence due to their non-normative bodyminds, which in turn creates distress further marking their bodyminds as non-normative. The concept of “psychosocial” is used by my interlocutors to express this interrelationship.

*Chandra* spoke of “psychosocial distress”, using it to describe her own distress. In survivor research as well as critical mental health literature, mental/emotional distress or simply distress<sup>35</sup> is often used to describe a person's emotional state in lieu of medicalised terms such as depression or anxiety (Plumb, 2011). If the term “distress” already distances experience from medicalised terms, “psychosocial” is doing something more. Similar to *Chandra*, *Naina* used the term “psychosocial crisis” to describe their experience. In both cases, the “psychosocial” part of the phrase, beyond just indexing one's emotional state, explicitly links that state to psychosocial factors.

What might they mean by “psychosocial factors”? Are “psychosocial factors” the same as “psychosocial lived realities” as mentioned by yet another participant? Both terms are used in these interviews to refer to the social structures beyond individual control which contribute to or cause disability. *Chandra*, referring to their early work with mental (ill)health in prisons, uses the term “psychosocial lived realities” as a shorthand for poverty as well as patriarchal and casteist structures which lead to incarceration. The mobilisation of “psychosocial” in this way moves us beyond and outside of a focus on just disability and distress and into the ways we can think about other social issues.

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<sup>35</sup> Within psychosocial disability literature and activism, there is an emphasis on experiences of madness which cause distress. There is a limited focus on experiences of madness which are not distressing. This is reflected in my PhD as well, since all of my participants described their experiences as largely distressing. For more on this, refer to Eli Clare (2017).

What creates a perpetrator? I would also be coming from that lens of understanding the psychosocial factors of crime...I got an insight into so many psychosocial lived realities. The number of people would be in jail just because they're poor people! (*Chandra*)

In both cases, perhaps an alternate term would be structural factors or structural lived realities. What does “psychosocial” convey that “structural” doesn’t? Does “psychosocial” refer to a new or different understanding of how structural factors influence and impact a person's life? What might be a “psychosocial framework”, a “psychosocial understanding”, a “psychosocial model”, a “psychosocial perspective” as used by different participants at different points? *Chandra*, who has worked across multiple intersections as a researcher and an activist, points to the interconnectedness of various issues as being central to a “psychosocial understanding”.

Engagement with, and exposure to, “trying to figure what is psychosocial and how we understand it” (*Laila*) is not limited to madness and mental distress but can and does happen in relation to other forms of marginality. *Laila* recalls her first encounter with the word, when she was in university, in the aftermath of the social and political movements triggered by what came to be called “the Nirbhaya case” i.e., the rape and murder of a young woman in Delhi which provoked widespread protests and a national conversation about women’s safety. While *Laila* did not expand on the relationship between “psychosocial” and gender-based violence, another participant *Ambika* talked at length about “psychosocial aspects” with respect to gender. As with psychosocial factors, “psychosocial aspects” was mobilised to understand experiences not directly related to disability. *Ambika* went on to emphasise that for them, psychosocial aspects of gender are concerned with the hierarchies of bodies and “how different bodies are accepted in this world”. Speaking about their engagement with psychosocial aspects of gender as a gender studies student and feminist activist, they spoke movingly:

We also looked at, you know, hierarchy of bodies...There are certain lives that are mourned more than others. There are certain losses that are mourned more or the people who are celebrated more, their losses are mourned more, and some lives are not mourned at all. So just the psychosocial aspect of that and what makes a life mourned more as opposed to others. (*Ambika*)

The above quote, particularly in the context of the ongoing genocide in Gaza (at the time of writing), stuck with me. By speaking in general terms, i.e., without speaking specifically about madness, mental distress, alternate/unusual experiences, we can begin to build bridges between different frameworks mobilised to understand the common concern which shapes the lives of many marginalised peoples—the differential values ascribed to lives and bodies.

A key component, and perhaps a surprising component, of how participants used the word psychosocial was to include the body, a site which is often neglected in both survivor literature and disability studies (Shakespeare, 2013). Several participants spoke of bodies as sites of social and structural violence, as part of social hierarchies, as sites of contestations, love, and hate, as something that is indivisible from oneself, and as the site which “mediates your relationship with the world” (*Ambika*).

I feel I view body as home, you know?... And home can be anything; it can be a place you want to come back to or the place you want to run away from. A place where you’ve seen a lot of abuse or a place where you want find peace. It can be both. It can be none. It can be all of them. It can be either/or. And I also feel like that’s what a lot of psychosocial disability is also as well, right? It is the social aspect, so it is the aspect of your body that impacts the inside, which is the soul, so that’s where I see the intersectionality for it (*Ambika*)

A psychosocial framework does allow me to look at it that way, that my body is in a constant state of negotiation with the society. (*Roop*)

This state of negotiation between self and society acknowledges the body without centring it. Psychiatric, medical, and psychological discourses focus on the individual and their mental state neglecting the role of structural factors. This critique is well established and is a central tenet within critical mental health, survivor research, disability studies, and has been highlighted as a one of the key gaps which psychosocial disability addresses (Cosgrove et al., 2019; Davar, 2013; Shakespeare, 2013; Sweeney, 2016). However, structural frameworks to explain or describe distress and/or unusual experience leaves the felt experience of the bodymind in the background. Feminist movements in India in the 1990s posited that women’s mental (ill)health could be understood as a protest against patriarchy (Addlakha, 2008). However, Davar (2013) critiqued this argument stating that such an explanation did not address the lived reality of pain and distress that women faced. She pointed to psychosocial disability, and disability more generally, as a way forward.

The role of the bodymind is also a contested and hotly debated issue within disability studies. The social model of disability and the activism that gave rise to it focussed heavily (and some argue exclusively) on social or societal factors, leaving the bodymind behind (Corker & French, 1999). The discursive turn within disability studies as well as the influence of queer theory brings to the forefront “the impaired body as a site of discourse production and a site onto which cultural discourses are projected” (Corker & French, 1999, p. 4). This analysis of “leaky bodies

and boundaries” views the disability experience as lying “in-between” society and the individual (Shildrick, 1997). It is this entanglement of bodyminds and social structures that is foregrounded in the way my participants describe “psychosocial” and what it has to offer.

#### **4.1.2 Understanding “disability”**

A question that permeates psychosocial disability activists’ and scholars’ thinking (including that of my participants) is what disability concepts have to offer to us? What does “disability” convey that other terms and concepts cannot or do not? Through an analysis of the usage of the term “disability” and its surrounding contexts in my interviews, I answer the above questions and pose new ones. My participants highlight the social model of disability as a central pillar of disability but equally go on to problematise the solutions it offers; the experiences it aims to capture; and the causal explanations it puts forward. For them, the social model is a useful starting point but fails to address the needs of those who are mad and/or multiply marginalised as well as those who are committed to dismantling structural oppressions. This is made particularly clear by critiquing the imagined neutrality of impairment and the artificial and rigid distinction between self and society within the social model.

In consonance with how my participants understand “psychosocial”, “disability” too represents a move away from medicalisation and places the onus of change on society rather than the individual, a central tenet of the social model of disability (Shakespeare, 2013). My participants highlight three aspects that they understand as central to the social model of disability.

First, the social model of disability creates a distinction between impairment as located within the body and disability as located within external social factors. As such, it primarily focuses on how disability is created/caused by inaccessible and hostile societal factors (Goodley, 2013).

So, it [introduction to psychosocial disability] allowed me to actually look at what it meant to use the word ‘disability’. I think I also had a very traditional notion of the word disability. So, I think it challenged my own notion and to actually see how disability was not necessarily impairments. The distinction between impairment and that which disables, social structures or barriers, to participation or being part of systems, was the way I [then] understood disability. (*Laila*)

Second, and following this identification of the ‘social’ as the problem and recognising disability as something which emerges from “environmental, attitudinal, and institutional barriers” (*Harsha*), the proposed solution of the social model of disability, also mentioned by my participants is “addressing institutional barriers” (*Harsha*), beyond healthcare:

It [psychosocial disability perspective] allows you to look at your distress not only as something that is under the health domain but also connected to livelihood and connected to other human rights. (*Laila*)

Finally, for my participants, a key intervention of the word “disability” is the inclusion of, if not a focus on, a broad range of “social aspects” of life such as “your caste, your class, your language, or lived experiences” (*Ambika*). Despite locating themselves in different contexts (*Ambika* in queer and feminist movements and *Harsha* in legal reform), *Harsha* mirrors *Ambika*’s insights on “hierarchies of bodies” and connects disability, critical race theory, and queer activism.

When I talk about disability as in a movement, activism, as a discourse, as a discipline. And fundamentally, the idea is that it’s a phenomenon wherein people...because of their ascriptive traits, things which are innate to them, are denied equality or equality of opportunity, because society puts up all of these different barriers that prevents them from participating on an equal basis with those who don’t have those ascriptive traits. And these are ascriptive, core, innate traits which people don’t necessarily have control over. And are, of course, considered undesirable by those who are in power. (*Harsha*)

In line with the critiques of the social model of disability outlined in Chapter II, my participants too problematise an outright and uncritical adoption of the social model of disability. This is in contradiction to literature which underscores the importance of inclusion within, and identification with, disability frameworks, particularly the social model of disability, as a key part of psychosocial disability. Schalk (2013) highlights her disidentification with disability studies emerges in part because “this collection of theories and practices do not seem originally intended for me” (para. 14). The social model of disability and disability studies at large is dominated by white global North people with physical and sensory disabilities (Bell, 2006; Meekosha, 2011). As such, there are significant gaps between the experience of my multiply marginalised global South psychosocially disabled interlocutors and the intended subjects of the social model of disability. My interlocutors problematise four key aspects of the social model of disability: one, the solutions offered by it, i.e., how would we address institutional barriers; two, its ability to capture people’s experiences, i.e., the forgotten body; three, its explanation of the causes of disability i.e., the assumption of a neutral impairment; and four, the need to look beyond the social and examine the structural.

First, as mentioned above, the commonly proposed solutions presented by the social model of disability to address institutional barriers to participation—reasonable accommodations—are

focused on making the world accessible to those with physical and sensory disabilities<sup>36</sup> and do not consider the experiences of people with psychosocial disability whose “reasonable accommodations are complicated” (*Neha*). *Naina* gives an example of doing a training with a feminist organisation and being unable to provide a clear list of their reasonable accommodations to the organisers. Elaborating on this, they told me that slight changes to the timeline of a workshop or small glitches such as a projector not working can make the event inaccessible to them. For them, it is difficult to envision in advance what their needs will be because they are “dependent on things which are unforeseeable”. In addition to these everyday practical concerns, *Neha* points to the need for larger systemic change i.e., “changing the nature of the world” to make it accessible for “people who have mental health conditions or psychosocial disabilities or who are autistic”. They go on to explain:

I feel like there is a lack of language for what we can ask for...other than changing the nature of the world, how are we going to find accommodations for us folks? Right? How am I going to help people, other than slowing down and not doing this insane event, right? Where is the accommodation for me? If we have agreed that this event has to go on, then I have to abandon the idea of having accommodations. It's the only way forward, you know? (*Neha*)

A second critique of the social model of disability offered by my participants is its neglect of the bodymind. The section above highlighted the entanglement of the social factors and the bodymind as an important aspect of my interlocutors' understanding of “psychosocial”. The social model of disability's rigid boundary between “where impairment ends and disability begins” (*RP*), i.e., where the bodymind ends and where the social begins, makes it unable to capture the experiences of some participants. Furthermore, within both survivor movements and research and the social model of disability, the opposition to over-medicalisation can slip into an opposition to *any* medical interventions. *RP* points out that, along with the side-lining of impairment, this works to obscure the needs of those who experience their body and its impairments as painful and distressing, for instance, those with chronic pain, chronic illness, or mental distress.

A third concern voiced by my participants is a common and major critique of the social model of disability, i.e., by separating bodily impairment from socially-produced disability, it obscures the

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<sup>36</sup> such as wheelchair friendly settings, sign language interpreters, closed captions, amongst others

fact that impairments are also produced socio-politically (Meekosha, 2011; Soldatic & Grech, 2014). My participants implicate societal factors as the cause of *both* impairment and disability.

And then in Indian context, in Dalit community, substance abuse disorder is really high. What they say that most of them alcoholic, you know, but imagine a community, especially manual scavengers, who has to go to the wrath of hell, clean gutters, be in shit hole. The person is getting intoxicated because this person doesn't want to be in touch with the body that time, right? There are times with me when I think I have done things intentionally like zoning out, or de-associations, like I think I've done that intentionally to not be in a situation and it is so harmful, it is very harmful, right? (*Roop*)

*Roop*, a Dalit queer activist, extends the social model of disability and enables a key strand of analysis: acknowledging that impairment, in this case mental distress and unusual experiences, is socially and politically produced.

The fourth and final critique is related to the need to examine structural, rather than social causes of impairment and disability. While many scholars within disability studies and global mental health conflate the two, some do draw a distinction (Crear-Perry et al., 2021). Social or societal factors are used to refer to the immediate social contexts within which people live, while structural is used to describe macro level causes of those social contexts. For instance, in the above example, the immediate social factor causing distress is the working conditions of manual scavengers, but the structural cause is Brahminical supremacy. The social model of disability, in both its explanations of the cause of disability and its proposed solutions, remains focussed on the social rather than the structural.

My participants employ “disability” to implicate social and structural factors in exclusion and discrimination, in line with the common understanding of the social model of disability. However, they draw on their experiences with Dalit, feminist, queer, and disability movements and trouble the social model of disability by questioning the nature of accommodations that mad and neurodivergent people need/want, by including the bodymind in their understanding of disability, by understanding impairments as socio-politically produced, and finally, by implicating larger structures of oppression which create the immediate living conditions causing disability. This reformulation of disability is an explicitly structural and political understanding of disability and distress.



### 4.1.3 Contextualising meaning: what words, said by whom, and for what purposes?

Just if I use it, I have a psychosocial disability, what does that mean to me? And what would it mean for someone else to hear that? (*SL*)

How you're using that word? Why are you using that word, where? Where are you coming from when you use the word? What are you trying to say when you use the word? (*Chandra*)

Questions of language, accessibility, strategy, and co-option are very alive in the minds and work of my participants. This sub-section expands on these questions by focussing on the particular positionalities in particular discursive contexts which shape the ways psychosocial disability and related words are being used by my participants. It serves to contextualise the preceding sections by highlighting three main points: one, the positionality of the person using the term changes what the term does; two, accessibility and the language of the term changes what it can do; and three, the employment of terminology for strategic purposes. These elements show that the meaning and utility of such terms are not static, but rather shifting and dynamic. Beyond the shifts over time, as *Abhishek Anicca* suggested in the quote in the introduction of this chapter, terminology is dependent on who is speaking, from what position, to whom, and for what purpose.

First, any term and its use are linked to historical and contemporary power imbalances and what a word means to the person saying it as well as “what would it mean for someone else to hear that [word]” (*SL*). Using the example of the politics of reclamation<sup>37</sup>, *Chandra* elaborates on the importance of placing the terminologies we use within their contexts:

When I say mental illness, it is also me reclaiming that word. *Haan matlab* [yes, I mean] it is a disability that is being caused or exacerbated or flaring up because of a lot of psychosocial factors, but if it exists it exists, right? Yes, it [mental illness] has a history in the way the word has been weaponised, right? But when people who relate to psychosocial disabilities also, use a word for themselves, it is a reclamation space. (*Chandra*)

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<sup>37</sup> Reclaiming a term is common to several movements. The mad movement as well as Mad Studies explicitly state that reclaiming the word ‘mad’ is one of their foundational aims. The word ‘queer’ has been successfully reclaimed by activists and scholars alike to the extent that it is now considered one of the more inclusive terms to use for LGBTQI+ communities. Crip theory, to a more limited extent, is reclaiming the word ‘crip’. (Menziez et al, 2013; Kafer, 2013; Rand, 2014).

In the quote above, *Chandra* is very clearly drawing a distinction between a person experiencing mental distress using “mental illness” to describe it and an external party doing the same. In the latter case, it is linked to the history of weaponisation of the term by medico-legal regimes, but in the former, it can be seen as an act of reclamation. *Chandra* goes on to add nuance to this argument by referring to the relational and dynamic nature of identities and positionalities. They are both a person who has lived experience of mental distress and a mental health practitioner. They emphasise that what the usage of a particular word does is dependent on the role they are playing in a particular context and the “power dynamics [between practitioners and users] in play”. For them and for others, it is important to understand who and why someone is using a term, the role of reclamation of a term which was historically used pejoratively, and the importance of external imposition of a term versus a self-generated term.

Second, almost unanimously, participants spoke about the limited settings where psychosocial disability as a term can be employed. Despite the assertion that psychosocial disability is a global South term (explored further in the next chapter), it is an English language term.

It is not simply the language of the term; certainly many English language terms have made it into the parlance of people within social movements and activism in India (Krishnakumar, 2024, p. 43). However, for some of my participants, psychosocial disability as a term is “more difficult for people to understand”. *Renu Addlakha* highlights that while it can be useful for personal identity, it is not a term that works (at the present moment) for mass mobilisation.

Because first of all, they don't know what the hell is mental, what is the disability about? What is the psycho? Like is it Hannibal Lecter or is it, you know, some mad woman in the attic? What is it? ... I think for its wider amplification, replication, understanding, appreciation, it's a bit opaquer. I think more work needs to be done on it. (*Renu Addlakha*)

Third and finally, there were participants who acknowledged the politics and limitations of using the term “psychosocial disability” but placed more importance on its use, and the use of all other terms, for strategic purposes. *RP*, who works on deinstitutionalisation and community inclusion, gives an example of having to use the language of mental illness when engaging with the mental hospital as part of their organisation's work and using psychosocial disability to engage with disability legislation.

Yes, psychosocial disability is the term that I use also, purely because of the social benefits that people can get, you know? Because it is also a part of the disabilities, and

that term becomes important also because they need to access the disability benefits for them. So, in that area, I use the word psychosocial disability. (RP)

Similar to the quote above, but in a very different context of institutional adoption of a particular term and highlighting the entanglement of professional lives and personal experiences, *Naina* gives their reasons for using psychosocial disability despite finding “most resonance with user and survivor of psychiatry”.

But I understand, and politically because I work with IDA [International Disability Alliance]<sup>38</sup>, etc, I must use the term ‘a person with psychosocial disability’ simply because that shows the paradigm shift. Even within WNUSP people were using the term psychosocial disability because that was really implying the paradigm shift. And I will identify myself as that, but there’s a part of me that kind of will always look at ‘user and survivor’ very fondly. (*Naina*)

In conclusion, the term “psychosocial disability” is mired in the politics of who is using it and for what purposes. This serves as a powerful reminder that there may be no singular understanding of psychosocial disability. Its use by different actors is complex, inextricably linked to their relationships with mental health, disability, and other positionalities, and is embedded within power relations and material conditions. The following sections unpack how these understandings of psychosocial disability are reflected in its specific uses—as a category, as an identity, and as a lens.

#### **4.2 The persistence of categorisation: boundaries of psychosocial disability**

I think it’s a very opaque domain...because psychosocial disability is such as undefined category, what the hell is it? (*Renu Addlakha*)

Any and all usages of the term psychosocial disability happens within the context of constant negotiations between my interlocutors’ desire for meaning making and the external imposition of a fixed bounded category of psychosocial disability. This section focuses on the concerns, institutions, and forces which maintain psychosocial disability as a bounded category. Further, it unpacks the utility of setting the boundaries of psychosocial disability; who and/or which experiences fit within those boundaries, and which are excluded; who decides this; and the role a

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<sup>38</sup> The International Disability Alliance is a global umbrella organisation of disability networks. It is hard to overstate the power and influence they hold in the global disability sphere, including donors, the United Nations, national governments. Website for IDA: <https://www.internationaldisabilityalliance.org/>

category of psychosocial disability with rigid boundaries plays. Through this analysis, I highlight how institutional factors, such as legal frameworks and material constraints, influence the terms of the debates and discourses surrounding psychosocial disability.

My analysis reveals that the criteria for defining psychosocial disability are closely tied to both institutional and cultural views on disability. In particular, the questions of who is considered psychosocially disabled are influenced by the historical context of medical classifications in disability laws, the cultural acceptance of certain forms of distress, access to financial support and welfare, and the desire for community connection. This situation leads to gatekeeping practices that reflect the broader effects of neoliberal policies and a competitive mindset. A bounded category of psychosocial disability, based on diagnosis, severity, chronicity, and visibility, enables acceptance into a disability movement which is wary of expansive definitions of disability. This in turn, opens up possibilities for inclusion within disability legislation and access to material benefits and protection. Beyond this, it also enables a sense of community based on common experiences. However, rigid categorisation limits/hinders the possibility of taking on disability identities, especially for those who do not neatly fall within its constructed boundaries. It hence works to exclude experiences and frameworks which are less legible as psychosocial disability and the people who embody them from the sphere of psychosocial disability activism and knowledges.

Friedner et al. (2018) state that all categories have a “constitutive outside, an impairment that is not included but could or should be” (para. 6). Although their analysis speaks specifically to the construction of ‘cross-disability’ in India, as discussed in Chapter II (Section 2.1.2), a similar argument can be made for the use of psychosocial disability as a category. While there was no consensus on what constitutes the category of psychosocial disability, all my participants agreed that this is a debate that is alive and active in many disability movements and that three elements were key in deciding where the boundaries of psychosocial disability lay—severity and chronicity; fluidity; and finally, the exclusion of specific experiences/illnesses.

First, several participants equated severity of debilitation as the distinguishing factor between mental (ill)health and psychosocial disability. For *Tara*, the category of psychosocial disability is limited to those who face severe forms of distress and voice hearing. By saying that “illness is seen more in a lighter fashion than disability”, *Bhanu Priya* justifies why disability is better fit for “giving [some experiences] the weight it deserves” and underlines the severity, the debilitation, the impact on functioning, and the permanence of some mental illnesses. For others like *Neha*, it was not the severity of the experience of mental illness itself, but rather the severity of violence

and institutionalisation that result from some kinds of mental (ill)health experiences. For instance, people who hear voices or have unusual experiences are more likely to face involuntary treatment, institutionalisation, and other forms of violence from society.

A second factor that participants brought up was the perceived and actual fluidity and lack of visibility of psychosocial disability which play a significant role in whether it is accepted as a disability by others.

Just because my life is so well curated now, you can't tell me that, "Oh, she's not disabled," because the fluidity plays such a huge role in it, that good days can mean that I might do things that I might not be able to do on another day, right? And that requires voicing of my concerns every time. And because I'm not a voicer of concerns, other people experience me as non-disabled. (*Neba*)

Finally, several participants mentioned their own or others' use of diagnoses and psychiatric categories to draw the boundaries of psychosocial disability. For some, depression and anxiety or 'common mental problems' are distinct from bipolar and schizophrenia or 'severe mental illnesses', with *Renu Addlakha*, a disabled academic and activist, stating that it is only the latter that should be included in 'psychosocial disability'.

If you have schizophrenia, you have psychosocial disability. But if I have stress related depression and anxiety, which is common because my life is really stressful, suppose, then—am I disabled psychosocially or am I not? I don't know. So, you see there's so many unknowns. (*Renu Addlakha*)

A commonly excluded experience was substance abuse and addiction. The participants who spoke about substance abuse in detail talked about how it is absent in both psychosocial disability movements as well as in broader cross-disability movements. It is interesting that all three of these participants mentioned addiction in relation to specific social and political contexts—*Anita* spoke of addiction as a response to the violence of militarisation; *Roop* in the context of Dalit communities; and *Ambika* within queer activism.

While one participant implicated the specific context of the "medically amorphous underpinning" of psychosocial disability for this confusion (*Renu Addlakha*), others emphasised that debates around who is and is not disabled are not limited to psychosocial disability but extend to a myriad of experiences. They spoke of their experiences of fatness, chronic illness, visual impairments, and difficulties standing for extended periods as liminal experiences that may or may not fall into the category of disability. In all cases, it is clear to me that the questions of

which experiences count as psychosocial disability is one that circulates within psychosocial disability and cross-disability activism despite the influence of the UNCRPD (which specifically refuses to bound disability) (United Nations Committee on the Rights of Persons with Disabilities, 2007). It is counterintuitive to me that a movement and its activists which so vehemently disagree with medical labels and categories would hold on to these rigid distinctions.

The debate about what can and cannot be included within cross-disability cannot be separated from the institutional factors which shape it. Mathew Kohrman (2007) in his exploration of disability in China asks a similar question: “by what means might institutional frameworks formally fix boundaries around what is disablement and what is not?” (p. 214). I believe it is the legacy of medical discourses within disability legislation in India which play a significant role in setting the terms of what is and is not psychosocial disability and explains the persistence of severity of illness in deciding its boundaries.

Disability legislation in India, both the Persons with Disability (Equal Rights and Full Participation) Act 1995 (PWD 1995) and the revised Rights of Persons with Disability Act 2016 (RPD Act), are anchored in medical understandings of disability (Dhanda, 2018). The RPD Act includes several categories of disabilities who are potentially eligible for benefits such as education or employment quotas. However, there are two caveats: First, there are differences between disability categories i.e., some disability categories are given more benefits than others. Second and more importantly for our discussion here, to be eligible for any benefits and entitlements under the RPD Act, a person must reach a “benchmark”—they must be certified as 40% or more disabled. This certification process happens by doctors in medical institutions. Despite the language of rights and social models of disability within the RPD Act, the institutional understanding of disability is still deeply medicalised and at its centre is the question of severity of disability (Ghosh, 2016). We can thus draw a line between medical discourses of categorisation and severity through to its legacy in disability legislation and how that legacy then permeates and sets the terms of debate within cross-disability and psychosocial disability activism in India.

It bears noting that how disability categories are constructed within the law itself is “not always conceptually pure” and that there are “socioeconomic factors that come into play” (*Renu Addlakha*). Cynically, but also probably realistically, they describe a “certain ad hoc ism” in how certain illnesses come to be recognised as disabilities. For instance:

You put Parkinsons in [the list of disabilities] why? So, maybe someone who is drafting it was in a position of authority said, “*theek hain* [yea fine] I see a lot of Parkinsonian

patients, *isko daal do* [put this in]" ...So, you know, some of these are not logically thought out, but maybe you don't want diabetes, cardiovascular disease, cancer, because so many people are having them.... So, leave those out. (*Renu Addlakha*)

Beyond what is or is not a disability and what is or is not a psychosocial disability, I ask what does psychosocial disability as a rigid and bounded category *do* for different actors in psychosocial disability movements? In other words, I am interested in what a bounded categorisation of psychosocial disability, and disability more broadly, enable and foreclose.

First, categorisation mediates who gets material benefits and who does not. In a context where social welfare is scant and benefits are limited, the constitution of psychosocial disability as a category is inextricably linked to the material realities (Friedner et al., 2018). In this way disability is both discursively *and materially* created as a category. *Tara* goes further to point out the impossibilities of furthering a conversation on disability towards debility due to these institutional frameworks.

My sense is that people might be against the very expanded definition of debility and might still be more centric on a disability framework because it's intrinsically related to obtaining government benefits and that's why there might not be possibilities of opening up that conversation. (*Tara*)

Second, I am reminded that these questions and tensions are neither abstract nor exclusively related to material benefits. *Tara* also argues for keeping psychosocial disability as a bounded category for reasons that are more intimate. She describes the debilitating nature of her psychosocial disability and the everyday struggle to cope with it as qualitatively different from the experiences of others who may face different, less debilitating forms of distress. For her, the conflation of all sorts of experiences into one category, erases the differences between those experiences and undermines the recognition and validation that psychosocial disability offers to her.

Because, you know, sometimes when I speak to people, and they think they understand me because they have gone through like mental health issues but the debilitation I face is not that easy which can just be termed off as depression or anxiety. Like the way I process emotions which is so difficult is entirely different, and so there is a sense of familiarity which isn't fair. There's this, like, I feel like when we put this under the broad umbrella of mental health, people assume a sense of familiarity with what somebody else is going through, which isn't the same. (*Tara*)

Third, the construction of psychosocial disability as a rigid and bounded category influences the possibilities of taking up a disability identity publicly. I interviewed a cross-disability activist who had never spoken publicly of their mental distress but did so extensively in the interview. When I asked them if they see themselves as somebody with a psychosocial disability, they answered in the affirmative but went on to clarify:

I don't want to take that space where—yeah. I don't. I feel like I'm not the, the best person to be talking about, the lived experience of it. (*Shivangi Agrawal*)

Also, I have seen, within the community of people with mental illness or mentally ill people, depending on how they define themselves, they're apologetic about calling themselves disabled. And I definitely count myself. I have a piece sitting in my drafts folder for a year and a half about coming out as disabled, but I haven't been able to. Because... am I really? (*Aman*)

The quote above speaks to the internalisation of the debate over whether one is really (psychosocially) disabled. Using the example of best-selling books, *Aman* emphasised that the common discourse of mental (ill)health is centred on those who have “either attempted suicide multiple times, been institutionalised, gone through institutional abuse and torture. Extreme suffering.” He adds that visibility in the form of “scars or some blade marks” are markers of such experiences. Referring to both severity and visibility, he added that “if you have those experiences then, “Then no problem. Welcome to the disabled club””.

While it now seems like “disability” as a common experience and category has existed forever, *Renu Adlakha*, a long-time disability activist and scholar, reminded me that not too long ago, “disability was of course not a category... We only had mental illness, and we had the blind and the deaf and the dumb and all that”. Additionally, many people referred to the hierarchies within the disability community pointing to the difficulties of being accepted as “disabled” and to have your “suffering recognised as disability” if one does not have sensory or locomotor impairments. For *Renu Adlakha* as well as for Friedner et al. (2018), cross-disability as a category divides the disability community rather than uniting them.

So, at a conceptual element, it [cross-disability] will work together... But when it comes down to the nitty gritty of everyday, engagement every day, practice every day, engagement on issues, then the separations come in. And in fact, I would say that there's a lot of fractiousness among these movements... in fact, the disability concept has created more fractiousness, in my view. Because all your people worked as different



impairment groups. You know, there's the blind, the deaf, the cerebral palsy. You worked separately, you thought of yourself as distinct identities, and you worked separately. Now you think you have similarities because you're all in the disability box, but you have different needs. You have different aspirations, and you're competing for the same resources. (*Renu Adlakha*)

Finally, there are some participants who acknowledge that this conversation is taking place but see it as a distraction from the potential offered by the concept of psychosocial disability. They express frustration with psychosocial disability understood as just a category under law and the gatekeeping that follows this narrow understanding. For them, psychosocial disability is not a means to acquire welfare benefits under disability legislation, rather it is reflective of people exploring and understanding their experiences. For them, psychosocial disability lives in realms beyond legislation and/or the external imposition of an identity, rather it is a process of making sense of their lives, their experiences, and the world at large. For *Roop*, a focus on bounded categorisations of psychosocial disability is an internalisation of limited institutional logics and runs counter to self-identification, a central tenet of psychosocial disability and user/survivor movements.

I'm like *aise certificate thodi na jaa rabe hain banane, woh toh wokeness main* young people are exploring... [I am like we are not going to go get a [disability] certificate made, 'woke'<sup>39</sup> young people are exploring themselves]. (*Roop*)

*Woh iss main bhot marr jaate hain, bas kis cheez ko aap psychosocial disability bolo ge aur kis cheez ko nahin* [they get stuck in this, what you can call psychosocial disability and what you can't] and I am like that's the entire idea of it—that let the person decide it for themselves, no? So, they become the state in itself. (*Roop*)

In summary, there is no consensus on what a category of psychosocial disability is, what it does or can do for people, and whether there is value in clarifying what such a category would mean. Themes of severity and chronicity are repeated in my interviews as parameters of assessing psychosocial disability. Further embedding these themes within the debate are the medical underpinnings of disability legislation in India as well as the public emphasis on certain extreme experiences of distress. While psychosocial disability as a clear bounded category is necessary for access to benefits under disability law, it can also provide possibilities of community based on

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<sup>39</sup> *Roop* is not using the word 'woke' as a pejorative as has become increasingly common. Rather, they are referring to people having a politicised understanding of mental health issues.

common experiences. Equally, rigid boundaries would necessarily exclude some experiences and people from claiming or even exploring psychosocial disability, a concern for some of my interlocutors who see the debate as an exertion of power through gatekeeping. Furthermore, bounded categorisation forecloses the possibilities of incorporating ‘crip’ frameworks which depend on an expansive idea of disability into psychosocial disability activism.

#### **4.3 Journeying into/through a psychosocial disability identity**

So, when I got exposed to that discourse, then I think there was no going back then, I really felt settled down. I felt arrived. (*Roop*)

Then sometimes I think to identify [as a person with psychosocial disability] also makes me feel like it's written in stone sometimes. And do I really want that right now? (*SL*)

I started each interview with an open question: “how did you come to psychosocial disability and how do you understand it?” As I outlined in my Chapter III, this first part of the interview was influenced by oral history methods and designed to enable my interlocutors to speak about whatever they connected most to psychosocial disability. One participant (*Chandra*) spoke for more than an hour about their experience of mental distress in great detail, interweaving personal struggles with an examination of structural factors causing or exacerbating these struggles. Others structured their responses according to their professional engagement with mental health and disability. Without exception, all participants spoke at length about their experiences of coming to psychosocial disability by describing how they came to identify politically, personally, and collectively as psychosocially disabled. For them, this identity was formed through engagement with the available discourses and frameworks which in turn shape and are shaped by medical and legal institutions. The literature indicates that a psychosocial disability identity is formed through a rejection of psychiatric labels and identities and through an affinity to or identification with a disability identity (Davar, 2015b). In other words, the literature indicates that psychosocial disability identities are both a counter-identification against psychiatry and an identification with disability. However, for most of my interlocutors, a psychosocial disability identity is neither a wholesale opposition to psychiatry nor an assimilation into disability. Their relationships to and engagements with *both* psychiatry and disability are formed through a process of disidentification with both.

For my interlocutors, as it was for me, coming to psychosocial disability identities, personally, professionally, and politically, was a project underlined by a desire to make meaning of their struggles, their disappointment with existing models and discourses, and an exposure to new

language and concepts. In doing so, they traverse through various settings, keeping some ideas and discarding others and finding new communities to fit into. They critically engage with psychiatric labels and discourses, often simultaneously rejecting their harmful aspects while using them strategically for survival and resource access. They have a complex relationship with disability, seeking and embracing elements of different explanatory models for distress, including the social model of disability, crip theory, and neurodivergence. Ultimately, my interlocutors, through their engagements with other people, ideas, and texts remain in a state of negotiation with various frameworks rather than fully embracing or rejecting any single one. Their journeys are not characterised by a linear progression from counter-identification with oppressive psychiatry to identification with liberatory disability; instead, it's a dynamic, strategic negotiation with these settings and discourses for survival.

#### **4.3.1 Making and unmaking meaning through/with psychiatry**

In a rare episode of unanimity within my interviews, every single participant expressed some desire to make sense of or meaning out of their experience of mental distress and/or alternate ways of being. This sub-section details participants' encounters with mental health systems in that journey and highlights four main points: one, the entanglement of personal and professional engagement with mental health systems; two, their overwhelming critique of psychiatry; three, and despite their critiques, the use of de-medicalised and psychiatric language concurrently; and four, their continued relationship to psychiatry. Through these observations, I emphasise that participants' relationship to psychiatry, and psy-sciences more broadly, is filled with ambivalence and continued negotiation.

First and resonating with my own experiences, participants sought out mental health fields, both in their personal lives and in their professional lives, when faced with distress and/or unusual experiences. The dominance of psychiatry and psy-sciences led participants to seek mental healthcare to make sense of their experiences. Several participants also sought workplaces related to mental health, pursuing degrees in psychology, joining mental health NGOs, and becoming therapists and social workers. For some, entry into professional mental health settings was driven by their personal experiences of distress, an attempt to make sense of their lives. For others, it was a desire to understand more generally "the human psyche" "from a social, cultural, political point of view, and not a purely biomedical, cognitive-led model" (*Harsha*). For *Aman*, their foray into mental health journalism was "an exercise in self-preservation" and only later "a political position". This mix of personal and professional (and political) is not surprising or unexpected.

Feminist and queer activists also highlight this entanglement of personal and political (Vanita & Kidwai, 2008).

Second, my interlocutors expressed that psychiatry and its related discourses were unable to completely explain their own experiences of distress or the experience of madness more generally. Some experienced traditional mental health framings, both as users and as professionals or students, as being overly focused on individuals and neglectful of the impact of structures, marginalisation, and social capital. The dissonance between personal de-medicalised understandings of life experiences and that of psy-discourses is highlighted by most participants and resonates with me.

There was some relief to know that [diagnosis]...but also at the same time I felt like that diagnosis did not—and was not able to cover just all of everything that I was going through. So, there was this sort of relief for sure, but there was also this sort of feeling of emptiness because I felt like it wasn't complete... (*Ambika*)

A stronger critique of psychiatry highlighted the active harms it caused by eroding a sense of safety, self, and agency. *Anita* implicated medication in worsening their mental health leading to not feeling “safe in my own body, in my own head”, “the loss of self” and removing/hindering “my say”. Psychiatry in practice minimised the possibilities of control over their life and eroded their sense of agency. The fight for informed consent and protest against involuntary treatment are key issues for survivor and psychosocial disability movements, and a motivating factor for the need for disability identities and frameworks. (Davar, 2015c; USPKenya, n.d.).

There are other related facets of psy-discourse that make disability so attractive as a framing. *Chandra* described how discourses of mental illness framed them as dangerous, wrong, or at fault. Further, psy-discourses were experienced as all-encompassing; they place the problem with the whole self, i.e., “everything is a symptom” (*Anita*); and they reinforce the idea that “your life is forever going to be like this” (*Anita*). *Kiran* described the very real implications of this, saying that with a diagnosis, everything you do, or experience becomes part of the ‘disease’. They give examples ranging from minor things such as smoking and drinking, which is often just a part of university life, being framed as “self-medicating” and more alarmingly symptoms of a serious and life-threatening illness being explained away as schizophrenia.

Third, and given their issues with psychiatry, it is unsurprising that many participants described their early experiences of distress and unusual experiences in de-medicalised language [“darkness”; “I was on a spectrum”; “sinking into hollowness”; “trauma”; “the time-space

continuum felt very weird”; “concerns with my body”; “burnt out”; “rapid disintegration of my mind”; “spiral” “scattered” “shattered”] or by using spiritual and religious concepts.

However, and in what seems like a contradiction, at the same time as they used this de-medicalised language, they often sought psychiatric or other mental healthcare. Further, they frequently referred to psychiatric diagnostic categories and labels to describe their experiences, and every participant made clear that their relationship to diagnoses was fluctuating and complex. While some participants experienced diagnosis as delegitimising their understanding of distress, others welcomed it, and all reflected on how their relationship to diagnosis changed over time.

I also don’t believe in diagnosis that much, but as a younger person, I think it would help me make sense. (*Chandra*)

I was diagnosed depression, anxiety, and PTSD, and then later I got diagnosed with borderline personality disorder.<sup>40</sup> I read about it, and I was like, “Oh, this is not me and these are not my conditions.” So, I rejected it...but at least getting a diagnosis helps you process it, whether to reject it or accept it. So that also is a journey. (*Bhanu Priya*)

Some referred to diagnosis as a validation of their experience of distress, a legitimisation of pain, a way to make sense of life, and a thing which “allows for comprehension” (*Bhanu Priya*). This desire for comprehension through diagnoses in addition to the expression of distress through de-medicalised and emotive language reflects the significance of meaning-making in my participants’ journeys into and out of psy-sciences.

Participants implicated aspects of the social and legal systems they must navigate for their ambivalence towards psychiatric labels and explanations for their distress. *Renu Addlakha* pointed out that within a context where prevailing ideas about madness are linked to intrinsic and negative characteristics of their personality, and are perceived as immutable, an illness narrative can provide a “certain kind of comfort”.

This is inherently a bad person, an evil person, a deviant person, a malinger, because we have all those characteristics plugged in. Or the person is actually sick. So, in that way, medicalisation in the early stages has its benefits. Especially when you’re thinking

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<sup>40</sup> For more information on the contestations around Borderline Personality Disorder as a diagnosis, refer to Reynolds (2018) and Watts (2024).

‘possessed by a demon and all that’, then if medicalisation is there, it’s useful. (*Renu Adlakha*)

When you are identifying with illness, you know that this illness is transient, that it’ll come and go if I take medication...For many people it’s cure. So, you will be cured. (*Renu Adlakha*)

Somewhat surprisingly, for some participants, it was disability that provided them with reasons to embrace a diagnosis. The cross-disability movement, and indeed the psychosocial disability movement, can be wary of people ‘claiming’ disability (Friedner et al., 2018). A diagnosis i.e., an institutional recognition of impairment, can be experienced as validation of disability and allay fears of appropriating a disability identity. Finally, both the ability to access mental healthcare and disability benefits are conditional on an acceptance of psychiatric labels. As an example, access to benefits afforded under disability legislation in India requires a medical certificate of impairment, in this case, a psychiatric diagnosis.

So, like I really had to take help of that curative model to be, like, to at least get access to help. (*Chandra*)

My interlocutors make strong and nuanced critiques of psychiatry, its labels and discourses; and at the same continue to use those labels and discourses. For them, a medical discourse can be delegitimising and is in contradiction to their preferred explanation of distress; and at the same time, a necessary and comforting option against discourses which equate madness with moral deficits; and equally a strategic choice to access resources. According to Schalk (2013), “the disidentifying subject takes up, uses, or revamps while leaving behind or being critical of other problematic or damaging elements” and does so often as a matter of survival (para. 15). My interlocutors in their journey through and with psychiatry, reject harmful aspects and practices of psychiatry and reformulate diagnostic labels from comprehensive explanations of experiences to strategically useful tools to navigate institutions. The relationship between psychiatry and my participants’ desire to make meaning of their distress is one that is complicated, to be continually negotiated, and has to be read within the particular demands of the social and material context.

#### **4.3.2 Coming into disability: old disappointments and new ideas**

By highlighting the ways in which participants express their difficulties with disability and describe their engagement with neurodivergence and crip, this sub-section underscores their continued search for languages, identities, frameworks, and discourses to make sense of the world.

The two issues with psychiatric discourses highlighted above—distress/unusual experience as a flaw or problem residing within the person and at the same outside of their control—work together to create a sense of not just having a problem but *being* a problem that cannot be escaped. *Anita* describes the freeing feeling of “realising that the problem wasn’t me, but the problem was the things that happened to me”.

While many of the participants were optimistic or at the very least intrigued by the possibilities of a disability identity, some pointed to the specific social factors that make it difficult to adopt. For *Neha*, it is difficult to adopt a disability identity because others “who work in the disability space don’t see me as disabled” and for *Raya*, psychosocial disability identity comes with the stigma associated with disability. *Abhishek Anicca*, who has lived with visible disabilities which have profoundly impacted his entire life, is searing in his assessment of disability within the public imagination.

What should you call people? ‘Disabled’, ‘differently abled’? “It doesn’t matter. If you search on Twitter, the most frequently used terms for people with disabilities are things like “*apang, kaana, kubada*.” ... [derogatory words for disabled people in Hindi] which still take deep root and show the stigma. So that’s a facile debate for me right now (*Abhishek Anicca*)

He goes on to say that people, even those using the ‘correct’ terminology still “believe in karma and look at disabled people from a karmic discourse [and] look at them as ‘sinners’ or ‘people who are misfortunate because of their past deeds’”. Others point to the facts that government’s usage of the word *divyaang*, “which means divine bodied” and according to *Aman* “[elevates] disability to some celestial level and further denuding their humanity essentially”.

A psychosocial disability identity is not de-linked from other identities and their consequences. *Naina*’s identity and experience as a woman subjected them to a unique form of psychiatric and patriarchal violence, foreclosing the possibility of adopting a psychosocial disability identity.

At that point of time, I was separated from my husband and that was something which was an issue between us, and he was constantly challenging my decision making, etc on the grounds of the fact that I had a mental health diagnosis and that I had been in a crisis. So, for me, it was not safe to really open up about being a person with psychosocial disability in the beginning. (*Naina*)

The search for a framework, an identity, something that makes oneself and the world explicable took some participants to other concepts such as neurodivergence, debility, and crip. *Tara*,

looking to address the critiques of the social model of disability outlined in Section 4.1.2, i.e., a lack of engagement with the political and structural causes of impairment and disability, draws on crip theory, and particularly Puar's (2017) concept of debility. In doing so, they coin a new term—"psychosocial debility"—which beyond disability, has the ability to convey:

people's mental and emotional distress as being intrinsically interlinked with the sort of lives we are living in the sort of environments and context we are in, but also, uh, an element of biological changes in where your brain functions. (*Tara*)

In other words, for *Tara* "debility" as a concept can bring together both the embodied and visceral and the structural and social. For them, like for Puar (2017) and others like Meekosha (2008), a "psychosocial debility perspective" can distance itself from the legacy of the dominance of physical disability in disability theorising and is useful in examining a range of environments like war, occupation, fascism, climate change which "can trigger trauma responsiveness in [a] person" (*Tara*).

Now if I go to a conflict region, for instance, in Kashmir, I don't think anybody there is going to say I have a psychosocial disability. And that might be too jarring for them, but the range of conditions that people have, I think those are all debility, right? (*Tara*)

If we understand environments from a psychosocial debility perspective, those environments can be anything like war, climate change. (*Tara*)

*Falak* spoke at length about their thoughts and questions about what crip and neurodivergence had to offer to them.

Crip is powerful. And it always... made so much sense. Crip was the thing in my spine that made the difference... crip gave me language... a very, very different kind of language. And I would not be here were I not able to access it. However, the distillation of that, like how do I enact my politics if crip is my politics? (*Falak*)

At this point, I had shed the research interview format, and we had shifted to a more conversational style—just two people trying to figure out how to navigate all the questions that mental health and disability raise for us. I asked her a question I posed in the literature review of this thesis—Can psychosocial disability crip mental (ill)health? *Falak* responded:

I don't think so. I think neurodivergence can [crip mental health]. Because [in psychosocial disability] we are losing of the body. Neurodivergence, in the history of it,



brings it back...[but] I think it's very difficult to consider neurodivergence in a lot of very concrete things like policy. (*Falak*)

While in the first section of this chapter I highlighted that psychosocial disability could include the body, that opinion is far from unanimous. For *Falak*, disability remains embedded in legislative settings and will not make room for the body. Psychiatry which is centred on the body is unacceptable as a discourse; it is oppressive rather than liberatory. On the other hand, neurodivergence for many is an unpleasant reminder of things like brain chemistry and wiring, the thing that psychiatry as a field was built on (Graby, 2015). For disability, neurodivergence is the inconvenient reminder that the work is so much bigger than changing legislation.

All participants expressed a deep desire to find a “different sort of language” and “a feeling that made sense” but very few, if any, have found a singular answer. The one thread that runs through all my participants’ stories and experiences is that wherever they position themselves, they neither reject nor fully accept any one discourse or setting. They stay in a state of negotiation with them, one that is continually shifting and evolving. *Falak* emphasises this when she says that “the political relational model is the one that makes the most sense to me *right now* [emphasis added]” but a few minutes later says that she doesn’t “have any of the answers”.

### **4.3.3 We, not I: shaping identities in and through community**

The journey through and into psychosocial disability is not an individual one, it invariably happens through and in community with others. All participants describe an encounter with people, texts, and ideas that led to their understanding of disability.

It was in interacting with her that I realised that she saw me as disabled. I kept saying I lived with chronic illnesses and mental health conditions and never really identified as disabled. And it was in my interactions with her that I discovered my disability as actually being a disability. That I could occupy that space... which was not something I was comfortable doing beforehand, right? (*Neha*)

Some participants refer to forming community and settings of care and healing, not as incidental to finding common cause but rather as one of the key things people do with psychosocial disability work. *Anita* described finding the Mad in America platform<sup>41</sup> as “such a source of

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<sup>41</sup> Mad in America website: <https://www.madinamerica.com/>

support” describing it and other psychosocial disability movements as “a community that I could be myself” and “space for my own healing.”

Recognizing common experiences of marginalisation and subversion of oppression is the first step in resisting harmful hegemonic discourses (Corker & French, 1999). The centrality of collectivity and community to my participants implies that forming collective community is not just the first step of resistance and knowledge generation, it is in itself an act of resistance amplified and made necessary in the face of individualising and atomising discourses of medicine and capitalism (Mingus, 2010). Speaking of her relationship with queer movements where she primarily locates her activism, *Falak* was clear that the movement was not about the individual “queer self” but rather about “queer relationalities”. *Falak* emphasised several times the power of finding out that “I wasn’t the only one, there was a whole community out there.”

Can we thus understand psychosocial disability as produced by collectivity and community, and as something that has the potential to produce collectivity and community? A shared identity of psychosocial disability is indeed powerful in many ways. It is well documented that a shared collective identity can be a powerful tool for activism, particularly for advocating for change within institutions (Damayanti, 2018).

Psychosocial disability identities form in and through collectivity. However, my interlocutors’ relationships to psychiatry and disability are varied and continually shifting. This diversity and dynamicity hinder the articulation of a common or shared psychosocial disability identity, what it would entail, its relationships to other identities, and to institutions and discourses. Furthermore, despite the importance of finding room to express their disability identity in community with others, it did not, as Shakespeare (1996) claimed, “transcend [all] other identities” (p. 109). My interlocutors understand their identities as fluid and multiple, with none acting as a primary identity.

We are not just one person at all times, our identities change and. Uh, yeah. And I said they're fluid, our identities and they are circumstantial. (*Anita*)

The varied experiences of people, the pathways they take to make sense of those experiences, and the hierarchies of power and privilege within psychosocial disability movements create a fraught environment. Jijian Voronka (2016) reminds us of the risks of conflating heterogeneous experiences into one essentialist identity. She highlights that “our experiences of madness/distress do not translate into meaning that we all share the same collective conceptual, positional, and material vested interests” and that by assuming so, “we risk erasing fundamental

differences among us that matter" (p. 197). The potential harm of erasure of different experiences and identities is magnified, perhaps, because coming into psychosocial disability is linked to making meaning of one's distress and finding community. *Anita*, who engaged extensively with the mainstream psychosocial disability movement as a younger person, describes her realisation of the power imbalances within it as "intimate". My participants are thus negotiating complex, and sometimes contradictory, relationships with not just social structures and mental health, but also with psychosocial disability themselves.

In their attempts to understand one's own distress and/or unusual experiences or the experience of madness more generally, participants traverse through many settings analysing the shortcomings and benefits of different models. My interlocutors who are "those with multiple intersecting marginal identities", were not the intended subjects of discourses which reject psychiatry or of disability discourses. For them, disidentification is "a strategic survival strategy" (Schalk, 2013, para. 10). Instead of the linear journey from oppressive psychiatry to liberatory disability suggested by the literature, participants describe a more dynamic relationship to these settings and discourses (Davar, 2013).

#### **4.4 Beyond categories and identity: psychosocial disability as a lens**

The sections above make clear that questions of psychosocial disability as an identity and as a category are complex and sometimes fraught. The former, in my opinion, both enables and hinders forming a collective community. The latter leads to tensions about who should count as 'psychosocially disabled' and who should be excluded. I argued in Chapter II that knowledges from marginalised locations create ways of understanding oppression and resistance often overlooked within the mainstream. I set out to action this theoretical point in my research—I largely interviewed those who occupied locations of multiple marginalisations and/or worked within movements which sought to address them. My interlocutors who are a minority within a minority come to psychosocial disability in search for a concept which can hold multitudes and accommodate the experience of madness and disability along with caste, queerness, military occupation, religion, and much more.

My interlocutors, through their work, knowledge, and analyses, construct a new way to mobilise psychosocial disability—*psychosocial disability as a lens*. As a lens, psychosocial disability is not simply an identity and a category. Rather it breaks down categorical barriers, creates room to understand the consequences of unjust and violent systems of repression on both disabled and non-disabled people, and facilitates a solidarity-based intersectional and inclusive activism.

In this sub-section, I first highlight why we need an intersectional lens to understand the relationship between distress and structural marginalisation. I follow this with a detailed explication of the understandings and actions which are enabled by considering psychosocial disability as a lens.

And slowly and steadily there was a lot more conversation around the social barriers that sort of prohibit people from living their lives to their fullest. And I started working with people with all sorts of intersections, of castes, of class, of religion, of gender identities, and that's what sort of opened up my mind. (*Ambika*)

The quote above explicitly draws connections between barriers that psychosocially disabled people face and the barriers that people marginalised by their caste, class, religion, and gender face. In doing so, it makes porous the boundaries between 'disabled' and 'non-disabled'. While this in itself would be a major contribution to the mainstream psychosocial disability movement, interviewees went further. Two interlocutors spoke of the concept of 'social suffering' as a way to look at "structural violence [and] exclusions and its impact on the psyche of people" (*JJ*). One of them referred specifically to the experience of Muslims in the context of Hindu nationalism in India (Bebaak collective, 2022). Both interviewees ultimately said that while social suffering was a useful lens, it could not fully capture the "psyche, the psychological suffering, distress". For me, this highlights that there is a search amongst those of us who work within multiple movements to understand the distress created by marginalisations of many sorts and build understandings and movements not solely rooted in assumed or shared experiences of distress.

Some of my participants explicitly used psychosocial disability to refer to people who are marginalised within society but would not be included under the category of disabled or consider themselves as having a disability identity. This understanding is aligned with many critical disability and crip ideas about disability, for instance, crip affiliation refers to those identify *with* crip but not necessarily *as* crip (Schalk, 2013). *Roop* draws a direct line between structural discrimination they experience as part of many marginalised groups and psychosocial disability.

I was speaking that you know how, Dalit queer in itself was enough, for enough to be psychosocially disabled. (*Roop*)

*Roop* goes on to give two examples of how oppression and psychiatrisation collude to pathologise certain behaviours. They give the historical example of 'drapetomania', a diagnosis used to pathologise enslaved Black people who attempted to escape slavery (Meerai et al., 2016). They give a second more contemporary example—substance abuse within Dalit communities,

especially those who are forced to do work that is unsafe and undignified without the necessary equipment i.e., manual scavengers or cleaning human waste. *Roop* explains that given these life conditions created by a violent caste system, it is only natural that people would turn to substances that could mitigate their experience of them. *Anita* also refers to substance abuse as a way to cope with the highly militarised and violent conditions of their community. In these examples, they state the response of society is to pathologise the behaviours which are a direct consequence of structural discrimination. Taking forward these explanations, psychiatry by pathologising the individual and placing the onus of change on the individual works to obscure and exonerate the oppressive structures (i.e., slavery, caste discrimination, militarisation) which create distress and other trauma-related issues. This observation has been made in other contexts such as the settler-colonial occupation of Palestine, misogyny and patriarchy in India, white supremacy in the USA, amongst others. (Addlakha, 2008; Jabr & Berger, 2015; Metzl, 2010) The landmark paper by Davar (2013) explicating the formation of a psychosocial identity for women in India also highlights these issues. However, whereas she points to a psychosocial disability *identity* as a way forward, I suggest, based on these interviews, that a psychosocial disability *lens* might be better suited.

Psychosocial disability as a lens enables four critical understandings and actions—one, marginalisation as disablement; two, a move beyond narrow legislative action; three, a focus on a wider range of issues; and four, building solidarity. I will explore each in turn.

First, psychosocial disability as a lens centres how marginalised identities can be understood as disabling. It allows us to understand why distress occurs, enables action against its root causes, and challenges the pathologisation of marginalised communities. It also allows us to challenge the discourses and scripts of resilience and “emotional resistance” which place the onus on the individual. For instance, the image of a long-suffering survivor who despite the strain of living under patriarchal structures is a source of strength and resilience. *Roop* spoke movingly about the “heartbreaking” burden placed on Dalit women whose experiences of Brahminical patriarchy lead to psychosocial disability in addition to the societal pressure to perform emotional resilience which in turn exacerbates/adds to their distress and disability.

Second, psychosocial disability as a lens enables us to move outside mainstream disability movements which, in India, are still primarily concerned with legislative and policy change. In my discussion of crip theory, I posed the question can psychosocial disability crip mental (ill)health? To crip something is to disrupt the status quo, to make explicit the assumptions that underpin exclusionary systems that regard certain bodies/minds as expendable (Sandahl, 2003).

Based on these interviews, I argue that “psychosocial disability” as a term does not do this inherently. However, activists use “psychosocial disability” in a myriad of ways, some more radical than others. The way “psychosocial disability” is used in this section, as a lens to understand all sorts of marginalised and non-normative experiences and identities, does have the potential to cripple mental (ill)health. Psychosocial disability as a lens disrupts the binaries between disabled and non-disabled and makes explicit that oppressive structures are interdependent and linked to each other. Psychosocial disability as a lens, hence, lends itself to an intersectional analysis led by those who are most marginalised. Used in this way, psychosocial disability comes closer to fulfilling the liberatory promise of Disability Justice (Berne, 2015).

Third, much like a ‘feminist lens’ instead of ‘women’s movement’ opened up a range of issues as a matter for feminism (Ahmed, 2017), a “psychosocial disability lens” opens up the possibilities for us to understand social issues beyond and outside of disability in ways that account for the structural, the emotional, and the social.

So, the way I look at things is crime is also a result of the system that we live in. I will go as far as to say that sometimes the people who commit crimes because of a lack of self-regulation... Oftentimes we see, I mean it is very psychosocial. (*Chandra*)

Finally, psychosocial disability as a lens not only allows for but builds within it possibilities for intersectional multi-issue activism. By employing it to understand the structures which oppress not just those who are deemed ‘mad’ but rather extending it to understand a diversity of oppressive structures which create a stratified hierarchical society, we can build solidarities between a range of marginalised groups.

Psychosocial disability will also include a lot of other things... So essentially how we understand psychosocial disability is that, and also looking at it from the intersectional lens, that you are at intersections or at positionalities, right, and live within a system and a structure that make those positionalities disabling for you, they cause disability. Therefore, casteism, the way we experience, people on caste margins are then also experiencing psychosocial disability, people on gender sexuality margins are also experiencing psychosocial disabilities. Therefore, in a way, being queer or being mentally ill is also queer, being disabled is also queer, yeah? (*Chandra*)

In her article on disidentification with disability studies, Schalk (2013) asks “how can we identify *with* social categories we don't identify *as* and how can this benefit us all? What are the similar, but not same, aspects of the lived experiences of people of color and people with

disabilities?” (para. 31, emphasis in original). Psychosocial disability as a lens, by drawing explicit links between the experiences of disabled people and other marginalised communities and by disrupting the boundaries between disabled and non-disabled, could provide an answer.

Actioning such an understanding of psychosocial disability in a context where rigid medico-legal systems are still dominant and actors within the psychosocial disability movements use the term in different ways is challenging and complicated. I do not know yet what such an activism would look like but like and through my participants, I want to find out.

#### **4.5 Discussion and conclusion**

Oppressed people resist by identifying themselves as subjects, by defining their reality, shaping their new identity, naming their history, telling their story. (hooks, 1989, p. 43)

This chapter asked and answered the question—how do psychosocial disability activists in India understand and construct psychosocial disability? Participants take different pathways and through a process of disidentification incorporate various aspects of psychiatry, crip, neurodivergence, and disability into their understandings of psychosocial disability. Beyond identity or category, psychosocial disability as a lens puts forth a new way of actualising the liberatory potential of psychosocial disability which can incorporate the political, radical, and structural understanding explicated in the first section of the chapter.

It is not surprising that any and all understandings of psychosocial disability are centred around the social, the political, and the structural. An examination of external factors causing disability is a starting point for contemporary disability movements as well as much of disability studies (Goodley, 2013). Aligning with the social model of disability, my participants describe psychosocial disability as a way of locating the ‘problem’ outside of the self. However, societal factors, for my participants, are not just important in the way they create disability and hinder full participation of disabled persons but are also implicated in how mental distress comes to be in the first place. They implicate a wide range of structural factors such as militarisation, casteism, fascism, communalism, conflict, gender-based violence, oppressive medical structures, amongst others and view these structures as interconnected and intersectional.

The emotional aspect of psychosocial disability is never far from their discussions of any other aspect of it. Interwoven between analyses of institutions and power dynamics, my participants talk about distress, pain, suicidality, and many other difficult topics with candour. They anchor their understanding of the world and psychosocial disability in those emotions. This is not

unusual—the very foundation of survivor research is that we can create knowledge from our experiences of madness (Faulkner, 2017).

It surprised me to hear my participants embrace the biological and the body. They did not reject the biological but rather reframed it as a canvas that the world leaves imprints on and then reads a certain way. Without exception, they all acknowledge how the body (and not just the mind) responds to structures, trauma, and violence. It is important to note that they do not centre the body i.e., they do not see it as the site where action or intervention should be focussed. Rather they see it as mediating the relationship between structures/society and distress/pain. This is made explicit by *Anita* and *Chandra* in discussions on intergenerational trauma recognising that the body is marked by and passes down signs of violence and injustice. In this way they put the body in conversation with trauma and the structures that cause that trauma.

Despite the tensions and contradictions presented by using psychosocial disability as an identity, as a category, and/or as a lens at different times by different actors in different contexts, there are three common threads that emerge through my analysis.

First and foremost, psychosocial disability is a term that is *ours*, our own articulation of our experiences. It is not imposed upon us by ‘experts’ and ‘authority figures’ but rather it is an act of naming ourselves and our experiences as a form of resistance which challenges the very authority of ‘experts’. As is key to many movements, including disability and mad movements, my interlocutors highlight the importance of being able to tell your story in your words (Narain & Bhan, 2009; Thomas, 1999). It is clear from these interviews that it is also a term and understanding that is dynamic and evolving. It is being continually formed and re-formed. I understand, through my analysis, that the very provisional nature of ‘psychosocial disability’ and its malleability in its current form imbue it with a power to counter the single story of psychiatry. It is a way to reclaim our “lost sense of self” (*Anita*).

Second, it is not just an individual act of resistance and knowledge generation. Carol Thomas (1999) argues that “without the counter-narratives of others who challenge social ‘norms’ we, as individuals, are trapped within the storylines of the prevailing narratives” and that it is through a collective re-writing that we can begin dismantling oppressive structures (p. 55). It is with and within collective community that we can re-form ourselves and our understanding of our experiences and the world. In my interviews, participants described encounters with people, texts, and organisations that enabled them to give voice to their disappointments with dominant discourses, and it was through community with others that they create alternate understandings and generate new knowledge. It is, however, important to point out that psychosocial disability is



not the only or not even the primary lens/identity/category that is foregrounded. Like all groups, movements, collectivities, the settings my participants found for themselves are infused with power imbalances, tensions, erasures, and exclusions. I will explore how these play out in the following chapters.

Finally, for my participants (and for me) psychosocial disability holds together different but inextricably linked aspects of experience and identity. My interlocutors through a process of disidentification are searching for and perhaps finding a way within psychosocial disability to “elucidate minoritarian politics that is not monocausal or monothematic”, but rather “one that is calibrated to discern a multiplicity of interlocking identity components” (Muñoz, 1999, p. 8). Unlike other available discourses, psychosocial disability seems to have the ability to hold together the biological and embodied; the emotional and felt; and the political, social, and structural.

You know also what I'm saying is that like I have struggled with this [caste] power dynamic, it's not making sense to me, so it's very a lot for my body. And I'm like rationally, I understand, I'm like emotionally I don't understand at all. And it becomes a lot for my body. (*Roop*)

Psychosocial disability, for my interlocutors, offers what other discourses do not. A psychiatric discourse favours the biological and neglects the structural and even the emotional (Cosgrove et al., 2019); progressive mental health and mainstream therapy settings centre the emotional (Ingle, 2018); and finally mainstream disability discourses focus on the structural and the political and avoid the biological (Meekosha & Shuttleworth, 2017). It is perhaps because psychosocial disability is a dynamic and evolving concept, that it can hold so many seemingly fraught ideas together. It can create a space that is ours, that can acknowledge the body and the biological, that recognises the need for healing the bodymind, and that mobilises to challenge oppressive structures.

In conclusion, different people understand and use ‘psychosocial disability’ differently. It involves bodies and emotions, situates them in social structures, challenges pathologisation, engages an intersectional lens, encompasses other forms of marginalisation, but is not without tensions and limitations. Previous literature suggests that psychosocial disability is a liberatory identity and category that goes beyond other discourses by emphasising the social constitution of distress and providing solutions and areas of action beyond the realm of psychiatry. I find that psychosocial disability indeed does do this, but that it is not inherently transformative and liberatory. Its use as a category and/or an identity, is constrained by debates around its

relationship to psychiatry, impairment and bodyminds as well as contestations around who should be considered ‘disabled enough’ to be included within psychosocial disability. I find that psychosocial disability is also understood as a lens. As a lens, it goes beyond what is indicated by the literature and becomes a way to understand the embodied consequences of structural marginalisation. Our understandings of psychosocial disability are dynamic and sometimes contradictory. *Renu Addlakha* suggests that “movements operate on two levels. There’s a conceptual element, and there’s practice. And often there’s a disjunct”. The next chapter focuses on how the conceptual understandings of psychosocial highlighted in this chapter are or are not put in practice within the realms of psychiatry and human rights.

*Interlude: on knowing systems viscerally*

*As I trace the contours of mental health and disability in India, I can hear echoes of my experiences. I remember sitting in psychiatric waiting rooms, the smells and sights of institutions, the harsh words of teachers and strangers.*

*Questions of legal capacity and guardianship are not impersonal debates for me but felt in visceral embodied memories of physical restraints.*

*Questions of disability frameworks and the like are inextricably linked to my survival and personhood in a world that is often harsh and unaccommodating.*

*Questions of marginality and intersectionality are reminders of how my experience is mediated through my gender, class, caste, disability, some of those mediations stark and visible to me and some obscured by my privilege.*

*Questions of alliances and solidarities are reminders of friendships I forged during experiences of injustice and a shared dream of righting them.*

*As I traversed the institutions of psychiatry, disability, family, education, and society, I have searched for myself in medical textbooks and in law, in memoirs and in fiction, in song and in poetry, in art and in films, in activism and in theory.*

*I have witnessed the worst horrors of psychiatry and thought to myself “there but for the grace of God” as the saying goes. But I know it is more accurate, although less pithy, to say “there but for the privilege of caste and class”.*

## **V. ‘Doing’ psychosocial disability: navigating institutions and discourses**

It’s one thing to recognise yourself in the rhetoric, it’s another thing to figure out what that means for your negotiations going forward. (*Falak*)

In the previous chapter, I argued that use of the word “psychosocial” and “disability” in combination with each other and with other terms reflects a desire and attempt to bring together different aspects of the disabled experience—the structural, the embodied, and the emotional. This chapter furthers my analysis by examining how psychosocial disability is ‘done’. It asks and answers how is psychosocial disability mobilised and ‘done’ and for what purposes within the context of institutional structures and the discourses that are foundational to it. The literature states that psychosocial disability represents a shift away from psychiatric medicalisation and towards human rights (Mehta, 2024). The importance of these two institutions—psychiatry and disability rights—was reflected in my interviews.

I approached my analysis of the institutions and structures that are leveraged/used/discarded within psychosocial disability activism in two steps. First, I conducted a thematic analysis to identify the institutions my interlocutors refer to. There are two main institutions that this analysis yielded, and these form the main sections of this chapter—psychiatry and health; and law and human rights. I then used tools from Critical Discourse Analysis (CDA) to examine how interlocutors speak about these institutions in the context of their own work and that of the mainstream psychosocial disability movement.

CDA framed my analysis in four main ways: first, my analysis is broader than just the institutional actions participants undertake; rather I also examine how these actions support and are supported by particular discourses. For instance, I am concerned with what activities my participants undertake vis-à-vis disability legislation, but equally with how my participants understand and navigate the broader implications of human rights discourses and the role of the state within their work. Second, I continue anchoring my analysis in understandings of power and marginality. My analysis goes beyond a description of the types of actions activists undertake but is also concerned with whose interests these actions further and whose interests are excluded. Third, I understand my interviews as text embedded within the broader corpus of knowledge and information about the topic. This is particularly key to this research for two reasons: one, I share a history and context with my interlocutors. This insider status leads to a wonderful form of intimacy where we know the actors and the histories of the movement but also creates gaps in the information offered by the transcript. Two, my interlocutors occupy a fringe location, and a significant portion of their interviews is a critique of the mainstream

psychosocial disability movement. It is necessary for me to provide the information about the object of that critique when and where necessary through alternate sources of knowledge. Finally, I understand knowledge production as linked to the social and political locations of my interlocutors. What they say, what they don't say, and how they understand their own and other's actions are never separate from their subject locations. This chapter, hence, is also concerned with uncovering the unmarked subject that these discourses and institutions speak about and speak to.

I argue that hegemonic ways of 'doing' psychosocial disability are predicated on an unmarked default psychosocially disabled subject which obscures, hinders, and de-legitimises other ways of doing psychosocial disability. Naming and dislocating this default subject position emerges from and lends itself to an intersectional analysis and practice of psychosocial disability. I use psychiatry and disability rights as examples of the mainstream psychosocial disability movement's exclusion of those who do not fit the upper-class and dominant caste subjects of the movement. I argue that total disengagement with psychiatry and an uncritical embrace of disability rights as a goal obscures potential pathways to answer a key question: "how do people who rely on accessing significant resources within a political economic context disrupt the very models on which they depend?" (Puar, 2017, p. 35). In other words, how do we work towards dismantling the systems we have named as harmful, when we also need them to survive?

My interlocutors practice systemic analyses and strategic engagements with psychiatry and disability rights and are constantly concerned with and evaluating the possibilities of complicity with harmful systems. This work emerges from, and results in, an intersectional engagement with the issues at hand. They understand and implicate several systems of oppression which work together to affect their lives. In other words, their work is informed not just by engagement with psychiatry and disability but also with caste, queerness, fascism, religion, and capitalism. Their engagements with institutions are not uncritical, rather they are strategic and respond to the demands of the particular context. Their ideas and actions within the realms of psychiatry and disability are underpinned by intersectional engagement, i.e., "people do not live single-issue lives", rather their lives are affected by a multitude of interlocking identities, experiences, and systems. Juxtaposing the work that my interlocutors do within the realms of psychiatry and human rights with the mainstream position, I argue that my interlocutors' actions constitute a form of radical reformism which not only expands how we 'do' psychosocial disability, but also who we consider psychosocially disabled (Marbre & Akbar, 2022)

The first section focuses on psychiatry. Situating my analysis within abolition vs reform debates within the user/survivor movement, I explore the implications of the third position presented by psychosocial disability—disengagement with psychiatry. I find that people who do not conform to the upper-class and dominant caste location are unable to completely disengage with the mental health system. Rather, my interlocutors approach psychiatry and its related issues—deinstitutionalisation, mental health legislation, alternate modes of healing, community inclusion—intersectionally and as such, their work adds nuance and complexity to when, how, and with what we engage. I argue that through the process of marking the unmarked subject of these debates, we can begin to create much needed distinctions between strategic engagement and uncritical engagement.

In the second section, I trace the role of legislative reform and rights-based discourses within the work of my participants. I examine the mainstream psychosocial disability movement’s reliance on this form of activism, how it came to be the central to the movement, and the critiques of this approach offered by my interlocutors. I argue that human rights as the lynchpin and goal of the mainstream psychosocial disability further entrenches a particular subject location as the default constituent and leader of the psychosocial disability movement. Here too, my interlocutors undertake actions which go beyond the mainstream’s single-issue engagement and through their systemic and intersectional lens, work to dislocate the unmarked subject of disability rights and in the process, expand how psychosocial disability is formulated and ‘done’ in India.

This chapter concludes that while the things that psychosocial disability movements do and aspire to do are presented as liberatory for *all*, there is an unmarked default subject position within those actions. When we examine that position, when we name it, and finally when we de-centre it, new critiques and pathways of action emerge. Informed by the abolitionist scholarship outlined in Section 2.1.1, I argue that my interlocutors, navigate psychiatric and legislative systems by undertaking activities which constitute a form of radical reformism or non-reformist reform, i.e., they undertake actions which are incremental but “attempt to get to the roots of the issues we face” (Marbre & Akbar, 2022, p. 1548) and “help us move towards the horizon of abolition” (Kaba, 2021, p. 96).

### **5.1 Psychiatry and the psychosocial disability movement: a continued haunting**

In India, you know, there is still the huge dominance of psychiatry in any issue related to mental health. I mean, they’re just like the emperors of the space. And they continue to be emperors of the space. (*Renu Addlakha*)

The spectre of psychiatry looms large within psychosocial disability movements across the world. The positions that psychosocial disability activists take vis-à-vis psychiatry have shifted over time and the mainstream movement in India has often chosen to disengage with the psychiatric system. However, my interlocutors, who are largely outside of the mainstream psychosocial disability movement, do engage with psychiatry, albeit uncomfortably and reluctantly at times. Their actions are shaped by strategic necessity, intersectional engagement, the limits of mainstream psychosocial disability movement's position on psychiatry, and the continued haunting of psychiatry in their lives and the movement more broadly.

To understand why psychiatry remains the presence that it is, even within movements that are either critical of or seek to abolish it, we need to trace the history of these movements, beginning with user/survivor movements. Some of my participants, especially those who have longer histories of involvement in the movement, spoke about the user/survivor movement, terminology, and framework as their entry point to the psychosocial disability movement. For them, the user/survivor movement enabled them to “use experience as a form of knowledge [and] see the possibilities of that in activism...in changing the discourse but also changing practice” (*Laila*). Beyond just an entry point to mental health and disability activism and movement, *Falak* emphasises that “a lot of survivor rhetoric is what is determining part of this political space”. The North-centric user/survivor movement's relationship with psychiatry is key in how it is viewed in the global South. The user/survivor movement does not embrace a singular agenda or strategy, rather it is splintered along two main positions vis-à-vis psychiatry: those who seek to reform the psychiatric system i.e., reduce over-medications, stop the use of restraints and seclusion, recognise legal capacity; and those who reject psychiatry as a whole and seek to abolish it i.e., dismantle the whole discipline and understand mental (ill)health through a purely social lens (Burstow et al., 2014). While I, and others, refer to this as the abolition vs reform debate, even amongst the abolition perspective, there is no consensus about what systems we need to abolish. For instance, some argue for the abolition of coercive and/or carceral psychiatry, some argue for the abolition of a separate discipline of psychiatry and pursue its incorporation into general health services, and some argue for the complete dismantling of psychiatry and its epistemological underpinning (Burstow, 2014). It is important to note that abolition within the user/survivor movement is specific to abolition of psychiatry and as such differs from anti-carceral abolitionist politics which aim to dismantle all carceral or punitive settings including but not limited to psychiatric institutions and includes within in critiques of multiple interlocking systems such as capitalism and white supremacy. Throughout this chapter I

use the word ‘abolition’ to refer to the user/survivor position on the abolition of psychiatry and ‘abolitionist’ to refer to broader abolitionist thought and action. (Burstow, 2014).

Psychiatry, whether it is to be reformed or abolished, continues to haunt our movements, and this section unravels the way the psychosocial disability movement and my participants engage with its ghosts. It asks and answers key questions—how is psychosocial disability ‘done’ in relation to psychiatry, what actions are hindered and enabled by psychosocial disability discourses, and what this way of ‘doing’ psychosocial disability tells us about the people who are ‘doing’ it.

The first sub-section looks at how psychosocial disability enabled the emergence of a third option to abolition vs reform—disengagement, i.e., ignoring, side-stepping, or refusing to engage with (to reform or to dismantle) the whole psychiatric system. The second sub-section unpacks how disengagement has affected the establishment and trajectory of activism within three key areas of mental health—deinstitutionalisation, mental health law, community inclusion and use of alternative modes of healing. I argue that intersectional and strategic engagements which emerge from the margins of the psychosocial disability movement pose a challenge to the continued centring of a cishet Savarna subject of these issues, open new forms of analyses, and centre issues and people often neglected in the mainstream. The third and final subsection deconstructs the abolition vs reform vs disengagement positions by asking deeper questions about both the imagined monolith of psychiatry and the imagined subject of the debates surrounding it. I argue that the mainstream psychosocial disability movement’s positions are shaped by its assumptions of a cishet Savarna subject of psychiatry, and the continued centring of this default subject position reveals the limits of such an activism. By examining the role of psychiatry in relation to psychosocial disability through the work and perspective of those who are multiply marginalised and those who use an intersectional lens, I reveal the potentialities and problematics of current approaches.

### **5.1.1 Escaping psychiatry**

This sub-section traces the psychosocial disability movement’s shifting position vis-à-vis psychiatry, embedding the emergence of a ‘disengagement with psychiatry’ position within the global abolition vs reform debates surrounding mental health activism. By following the work of Bapu Trust and Bhargavi Davar as an example, it outlines how disengagement and psychosocial disability became the key pathways to liberation for all and the implications of the shift to disengagement for the movement and the people within it.



Many interlocutors refer to the work of Bhargavi Davar, and more broadly of Bapu Trust which she led, when they speak of their involvement with psychosocial disability movements. Some refer to her as their mentor, others refer to Bapu Trust as being instrumental in their “entry point” to psychosocial disability, and yet others spoke of their engagement with courses, programmes, and initiatives undertaken by Bapu Trust. Interlocutors who entered the field in the early 2000s as well as those who did so as recently as 2018 mention Bapu Trust and Bhargavi Davar as central figures in shaping their early understandings of psychosocial disability. As reflected in the literature review in Chapter II, Bapu Trust represents a significant part of the mainstream psychosocial disability movement. It is, hence, instructive to explore how my interlocutors remember the work that Bapu Trust did, how it changed and evolved, and its implications as not just an example of, but rather the epitome of how a third option for the abolition vs reform debate emerged.

### *Early engagement with user/survivor*

Davar (2018) in her history of the psychosocial disability movement recalls the introduction of the user/survivor terminology and framework in India as a key moment, an observation shared by my participants who were active at that time. She gives varied reasons for why user/survivor was not an easy fit for those in the global South. Using what I knew about how my interlocutors described themselves, I probed and asked them to explain some of the implications of using the user/survivor terminology.

If you look at it in terms of chronology...users and survivors of psychiatry came up first. And of course, the critiques against that is that it's a very medical model because it's really talking about psychiatry. (*Naina*)

The term user is interesting because user/survivor comes from, of course, engagement with biomedical systems. (*Falak*)

My understanding of user/survivor and disability coming from TCI's<sup>42</sup> approach to it [is that] user/survivor is a lot more global north. (*Anita*)

Two main and interlinked critiques of the user/survivor paradigm emerge from my interviews. First, it is framed vis-à-vis the psychiatric system. Whether it is entirely opposed to psychiatry

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<sup>42</sup> TCI, i.e., Transforming Communities for Inclusion is a cross-border initiative which initially focussed on the Asia-Pacific region and is now a global network. Davar and Bapu Trust played a significant role in its conception and expansion. <https://tci-global.org/>

(the abolition approach) or wishes to create better conditions with the mental health system (the reform approach), it centres psychiatry as the site of activism. Second, it is read, to an extent, as a global North concept, one that emerges through and from a particular context of psychiatry. In the global South, psychiatry is unevenly distributed and as *Naina* puts it “[User/survivor] might be alienating for people who’ve never experienced a psychiatric system because of the fact that services don’t exist in their countries.” User/survivor terminology and paradigms, by ignoring the colonial roots of psychiatry in the global south, hence becomes complicit in that coloniality.

These arguments are well represented in the literature on psychosocial disability in the global South (Robb, 2008). Within the Indian context, Davar (2018) argued that the term user/survivor did not capture the realities and/or needs of those with lived experience of mental (ill)health stating that this “identity emerged from a context which was ‘white, north country, institution-based psychiatry, high income’”. She posited that psychosocial disability provided a “subaltern narrative” based on local contexts (para. 2). It is within this context, and as a response to these critiques, that psychosocial disability emerged. It materialised, in part, to de-centre mental health systems and in this way, also to side-step the debates inherited from mental health-centred activism.

Although psychosocial disability purportedly moved away from user/survivor terminology and all its baggage, when asked about the main points of tension within the psychosocial disability movement, *Tara* responded that “the big ones [are] abolishing versus reform”, i.e., “some people are around better human rights within institutions; some people want complete abolition of institutions”.

#### *Psychosocial disability: a different terminology and a different paradigm*

Many interlocutors remember the shifting priorities of Bapu Trust in the 2000s as a pivotal point in shaping what is understood as psychosocial disability activism. In its first few years, Bapu Trust focussed on community mental health, deinstitutionalisation (especially of women), and creating awareness of a rights-based and client-centred approach to mental health (Mills & Davar, 2016). Following India’s ratification of the UNCRPD in 2007, the term psychosocial disability, and disability more broadly, entered the lexicon and work of Bapu Trust, and other mental health organisations within India and elsewhere in the global South. The literature mentions two key implications for this shift—a move away from north-centric and psychiatry-centric discourses; and the potential inclusion of action in other spheres of life (Damayanti, 2018). Key to this shift was also a building frustration with the psychiatric and mental health establishment.

By the time I had joined, the leaders in Bapu Trust were not entering the mental health space as much. They'd already moved away from it... [and] all the groups that were using the term mental health. BT was not that involved in a lot of the conversations that were taking place here. Partly, I think because the conversations seem the same, they're not changing as much in time. (*Laila*)

Many of my participants either entered the movement at this moment or remember the shift as being pivotal. Psychosocial disability provided a third option to the abolition vs reform debate which had plagued mental health activism: *disengage* i.e., ignore, side-step, refuse to engage with the psychiatry. This meant disengagement with the whole system—psychiatrists, mental health workers, asylums, and the legislative infrastructure that governs these actors and institutions. This disengagement position was a move away from a work which “pitched us against medical establishment” (Davar, 2018, para. 3); rather disengagement would mean shifting our energies and efforts towards activism and advocacy related to housing, education, employment, communities, and other non-health spheres of life.

The three approaches/positions—abolition, reform, disengagement—are not mutually exclusive in practice and some actions overlap. Aligned with abolitionist organising, abolition of psychiatry within survivor movements most commonly works in three spheres—engagement with psychiatric systems in order to dismantle it (for instance, deinstitutionalisation efforts); expanding community and/or non-carceral mental healthcare (for instance, lobbying state actors to allocate funds differently); working on issues outside of psychiatry (for instance, peer support, housing, employment, etc.). A reform position focuses on the first two spheres—engagement with psychiatry and with community healthcare—but largely ignores the third. Disengagement as a position shares many of the same critiques of psychiatry as abolition and at the beginning was an attempt to shift priorities and resources into issues outside of psychiatry. This strategic choice slowly morphed into a rigid position: one can neither abolish nor reform psychiatry, just work outside of it. Psychosocial disability and disengagement with psychiatry was at first mobilised as a way to *include* other aspects and spheres of life and work. However, it slowly evolved into a way to *exclude* any conversations and work about mental health and psychiatry.

### *Schisms and splinters*

While the inclusion of non-psychiatric facets of life was critical for the gains that the psychosocial disability movement made, the effect of the subsequent exclusion of all mental health related action created schisms within the movement and had implications for the people

working within the movement. This exclusion solidified the disengage position, as Bapu Trust and other affiliated organisations refused to work with, in, or even against psychiatry.

And I remember psychosocial disability as an idea was something that was floating around in corridors of Bapu maybe around 2006 or 7. And we were trying to make sense of it. And one of the reasons I left, actually a lot of difficulties, [was] because it felt like what we had been trying to do for 5-6 years, suddenly it had been turned into [an] extension of medical model and not really anything radical. (JJ)

As the quote above illustrates, the type of work that constituted psychosocial disability activism changed. Community mental health, deinstitutionalisation, mental health legislation reform, mental health awareness campaigns, and peer support were all now deemed activities not in line with the new paradigm of psychosocial disability but rather a part of the reformist agenda of the user movement. Even campaigning to abolish psychiatry still centred psychiatry. The medical model, within this new position, was not just to be fought against, but not engaged with at all.

Beyond the change in the activities of the movement, some actors within the movement found themselves designated *persona non grata*. The structure of the existing movement, wherein the broader ecosystem of global disability organisations and international funders perpetuate, maintain, and uphold the power of a small number of activists and organisations, enables a small section of the movement to shape the discourse and the agenda of psychosocial disability, and hence shape what *isn't* psychosocial disability. Activists who are peripheral to the centre of power within the movement are left with limited choices—toe the line and repeat the narrative; or be excluded, ousted, or labelled a betrayer of the movement. *Madhu*, a veteran activist who was a part of the early psychosocial disability movement and now runs her own organisation, describes the response of some activists to her continued work with institutions:

So, lot of other activists have said that “She works with institutions. And therefore...she should not have a seat at the international advocacy table”, which I find very ridiculous...So I think this either or none vision impacts real time activism... (*Madhu*)

In summary, the trajectory of psychosocial disability activism in India started with early engagement with user/survivor frameworks and terminology and at the same time, a recognition of its limits within the global South context. Psychosocial disability emerged as a framework which allowed for the inclusion of non-mental health facets of life and to side-step the abolition vs reform debate which plagued user/survivor movements. However, psychosocial disability activism gradually morphed into a complete exclusion of and disengagement with psychiatry and

its apparatus. Subsequently, schisms emerged within the psychosocial disability movement which excluded certain people and issues from the realms of psychosocial disability activism.

### 5.1.2 The costs of disengagement

Engaging and not engaging with [psychiatry] is a privilege. Who gets to engage with it and when is a question. Who are able to live without it is another question. What are other support systems? Alternative mediums? (*Bhanu Priya*)

In the quote above *Bhanu Priya*, who runs a small disability and anti-caste collective, links the possibilities of disengagement with psychiatry to one's social, political, and economic locations. My interlocutors, most of whom are not from the mainstream psychosocial disability movement, continue to engage with psychiatry. This sub-section explores how they navigate the psychiatric system as well as the *abolition vs reform vs disengagement* debate. I argue that disengagement as an overarching strategy for psychosocial disability fails when we de-centre the upper-class Savarna urban elite as the main subject of the debate; rather those who are multiply marginalised must employ strategic and intersectional engagements. This intervention is best illustrated by taking up three related areas of work which are prominent in my interviews—one, deinstitutionalisation; two, the Mental Healthcare Act 2017 (MHCA) and more broadly the role of mental health legislation; and finally, the increased focus on community and alternatives to mental healthcare.

My interlocutors, informed by their own lived experiences of marginality as well as their involvement in intersectional movements, critique the disengagement position of the mainstream psychosocial disability movement. They draw distinctions between uncritical and strategic engagement. The latter refers to engagement with institutions and discourses that they have identified as harmful (such as psychiatric institutions) in order to reduce their impact on individuals as well as attempt to bring about systemic change. They do this as a one part of their intersectional actions related to mental health systems. While remaining critical of mental health legislation, they nevertheless recognise its power in shaping the lives of people and hence continue in their efforts to minimise its harm. Their intersectional engagement, based on a lens which understands that different systems of oppression work together to affect the lives of those who are multiply marginalised, enables a nuanced analysis and critique of mainstream approaches to deinstitutionalisation, MHCA, community inclusion, and alternative frameworks of mental health. In doing so, my analysis reveals that mainstream approaches not only exclude certain issues but also actively harm those who do not conform to their assumed and unmarked subject.

While other actors within broader mental health movements/activism have also engaged with these three areas of work, I am specifically interested in the activism of those with lived experience of psychosocial disabilities. As such, I do not explore in detail the relationship of my interlocutors, their work, and the work they critique with broader mental health activism. Furthermore, it is also worth noting that there is no cohesive movement concerned with mental health systems in India.<sup>43</sup>

*Deinstitutionalisation: escape from the asylum*

Everyone I interviewed unanimously agreed that the violent excesses of psychiatry are a constant concern. Psychiatry as it is practiced in India (and elsewhere) is replete with human rights abuses. This is acknowledged and discussed in almost all bodies of literature including global mental health and most forms of Indian mental health activism which espouse a reformist rights-based psychiatry as a solution (Kelly, 2016). References to, and memories of, specific forms of violent practice came up again and again in my interviews—over-medicalisation; violence against queer people; physical restraints; long term and coercive internment in psychiatric facilities; lack of informed consent or any consent at all. I found myself nodding along to these bits of our conversations, finding my life in these harrowing stories.

When I was studying in NIMHANS, they were doing behaviour modification for homosexuality. So, they were trying to cure people. I was posted in what is called a behavioural medicine unit, which is a behavioural therapy unit. It's a one month posting that you to be there. And of course, there was a young gay man who came, [with] who they wanted to do this aversion therapy. They put strips, sort of, put these electrodes on your wrist. And they will show you these slides of semi-nude men and women. This was a man. So, when he would, he was shown the slides of men, he was given this, what is called as a mild shock. (JJ)

JJ is a queer disability activist who, in the quote above, is describing their experience as an intern in or around the early-2000s within NIMHANS, the premier psychiatric hospital in the country,

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<sup>43</sup> There are multiple actors and agendas which work in and around mental health activism separately from each other. For instance, global mental health works on access to mental healthcare, rights-based reforms, and community mental healthcare (Mills, 2014). Indian psychoanalytic traditions, informed by their connection with traditions in Latin America, have critiqued colonialism and its legacies but remain largely an epistemological and academic exercise (Nandy, 1995). Persons and organisations focussed on general health sometimes include mental health but do so as an afterthought. Some parts of mental health activism want more psychiatric systems, including institutions; others work on reducing stigma. Prison abolitionists in India have not focussed on psychiatry beyond forensic psychiatry and the mental health impacts of imprisonment (India Labour Solidarity, 2025).

one that I had the misfortune of engaging with as a ‘patient’. As they described and talked about what they witnessed as an intern there, I acknowledged:

It’s so weird for me to hear you speak about such deeply familiar spaces differently because I’ve been in those corridors of NIMHANS I think endless times. Like I’ve, I know that space so well, but I don’t know it at all from like the perspective you’re talking from. (*Akriti Mehta*)

Within an otherwise formal interview, this crossing of paths opened the possibility for a quiet sort of intimacy. After the interview, I reflected on my own memories of the place, the threats of involuntary institutionalisation from various doctors, the instinctive hiding of my queerness, and equally how protected I was from the worst aspects of the institution because I was at the same time a middle-class clinical psychology student. I mention this, both as a methodological point, and an empirical one: a reminder that for me and my interlocutors these are questions of theory and work, but also of survival and trauma.

Many other interlocutors connected psychiatric violence to patriarchal violence, giving examples of women who were involuntarily committed to psychiatric institutions sometimes for decades by abusive husbands. Beyond the obvious and explicit erasure of liberty of those institutionalised, *Laila* and *Deepu* who have worked with institutionalised women extensively, describe a harrowing erasure of personhood and humanity.

In the institute that voice was just non-existent. If you ask somebody, “What do you want to do?” Nobody can answer that question because ‘wants’ are not something that are enabled or allowed for in the institute. (*Laila*)

When you’re institutionalized, you’re a creature, you know, you’re not a human being anymore. And it’s taken away. Every bit is taken away from you. (*Deepu*)

The prevalence of such practices meant that from the early days of the movement, everyone within the movement agreed that deinstitutionalisation and advocating against violence within the institution should be a priority for the movement. However, within broader society such a challenge to the mental health infrastructure as well as the government and its mental health policies was still “a very powerful political statement” (*Madhu*). In their description of this period (early 2000s), several participants note that working with and within the institutions was central to the project of deinstitutionalisation. The work during that period included advocating for individual cases, providing recently deinstitutionalised people with resources, pushing for bigger changes through policy changes, and imagining what “deinstitutionalisation of mental health

would look like in the real space” (*Madhu*). Elsewhere in the interview, *Madhu* describes how the work of the most prominent activists and organisations gradually moved away from abolition of psychiatric institutionalisation to a disengagement with psychiatric institutions. While there was unanimity within the movement on the harms of and the need to abolish the psychiatric asylum, there were significant divergences on the best strategies to accomplish this. For *Madhu*, disengagement was akin to “throwing the baby with the bathwater” and an act of abandonment of those still institutionalised.

Many of my interlocutors do still work on the larger project of deinstitutionalisation, strategically working with and “inside institutions with the politics of bringing in systemic change” (*Madhu*).

And in twenty-three years, people are getting independently discharged. Whether they’re going back home, whether they are loitering in the streets, whether they would lie on the pavement. I mean, finally, we have been able to make a paradigm change in the thinking of the government where they have taken the risk of letting people go, including women. (*Madhu*)

For *Madhu*, and other interlocutors, their engagement with psychiatric institutions is not uncritical. It is a strategic engagement towards the broader goal of deinstitutionalisation, i.e., they do not believe that engagement with psychiatric institutions is the only way to achieve deinstitutionalisation; rather, it is one prong of a broader effort to bring about their abolition goals. It is also not without discomfort. *RP*, a long-time activist, reminds me and herself that strategic compromise or engagement can turn into complicity with the institution i.e., “when you work in an institution you kind of become like that institution”. The absolutist disengagement position of the mainstream psychosocial disability movement makes no distinction between strategic engagement and uncritical engagement and consequently paints any compromise with the institution as complicity with it. However, my participants engage with the institution in the short term to further their long-term goals of full deinstitutionalisation, i.e., they undertake their abolitionist goals through a process of engagement with the system.

#### *Mental health legislation: to be or not to be*

Disengagement with the psychiatric system included a disengagement with mental health legislation, or the Mental Healthcare Act 2017 (MHCA) in its latest iteration. My interlocutors in their description of engagement with and analysis of the MHCA focus on three related areas—one, debates about the very existence of the law; two, the differential impact of its implementation; and three, the provisions it makes for legal capacity and guardianship. I argue



that disengagement, in all areas, excludes/fails many people in India for whom interaction with the MHCA is not optional and obscures the gains made by the Act, albeit limited, for specific communities. An intersectional lens, such as my interlocutors adopt, reveals pathways for undermining Brahmanical supremacy and heteronormativity within the context of a ‘failed’ effort to reform or abolish the MHCA.

First, in the run up to the MHCA the psychosocial disability movement was engaged in both an internal debate over the need for a mental health law, as well as government consultations on the draft bill. There was a part of the psychosocial disability movement, epitomised by Bapu Trust, who after adopting the language of psychosocial disability sought to abolish mental health legislation altogether. *Laila*, who worked closely with the mainstream psychosocial disability movement during those years, said “[it] did not believe that the act [MHCA] should have been there”. At first, the movement argued that persons with psychosocial disability will be covered by disability law and the health bill making MHCA redundant. The project at that time was one of *inclusion* within the disability legislation complemented by campaigning to stop the passing of the MHCA. However, once the MHCA was passed in 2017, the disengagement position turned to *exclusion*, a complete refusal to engage with it at all. *Laila* describes what that meant as they sat in consultations “trying to decide the rules of the act”.

I can critique it, but the act is already there. It has already been passed. And so, I felt like this is a very different way of thinking, because now you have to work within this Act structure. So, I can sit outside this structure say that “We shouldn’t have this,” but it is already there. (*Laila*)

Transcribed quotes cannot fully capture tone of a conversation, nor do they capture the shrugs, the shaking your head in disbelief, or rolling eyes, so the readers will have to trust me when I say that *Laila* made sure I knew that they thought this entire situation was absurd. The disengagement position in its absolutist stance did not alter its position once the Act came into law. Further adding to the absurdity was the insistence that we as persons with psychosocial disabilities can flee psychiatry through disability legislation. The RPD Act, positioned as a haven from psychiatry, brought us, i.e., the psychosocially disabled, right back to psychiatry and so the haunting continued.

And so, what we have is a bunch of people, including the psychosocial people who are running from the biomedical, not acknowledging that the biomedical is critical point of intersection for a lot of people, including to get a disability certificate, including to get disability housing, including to engage with educational institutions. (*Falak*)

Second, and beyond this legislative dilemma, lies a more important reality—regardless of our political positioning on whether the MHCA is needed or not, once it is law, it governs the life of people “who are part of the system on behalf of whom we are also speaking” (*Laila*). As with all legislation in India, this is especially true for those coming from marginalised locations. *Laila* refers to a community mental health project impacted by the MHCA; one that services an urban poor slum community, many of whose residents are Dalit Bahujan, and all of them are working class. From my own experience, while mental health laws have impacted my life presenting themselves as a pervasive threat of involuntary commitment, my class and caste location also enabled me to persuade/bribe my way out of the consequences (imprisonment) of trying suicide, a criminal offence at the time. This is not the reality for most people living in India and presents the most biting critique of the mainstream psychosocial disability movement actors, who hail from urban English-speaking Savarna backgrounds. From that social and political location, we (and I include myself here) can disengage with efforts to reform mental health legislation, choosing to ignore it entirely. However, those occupying marginalised locations must deal with it, and the disengagement strategy hence fails them.

My interlocutors, especially those who work in other movements, very much acknowledge this reality and undertake work related to the MHCA—monitoring its implementation, especially its provisions for user representation; advocating for individuals’ rights to advanced directives; conducting research on how specific groups like trans communities are treated under the law; raising awareness within communities about the rights we are granted under the law. It is not an uncomplicated position, nor is it a wholesale acceptance of the law. As *Roop* tells me “I’m not rejecting the law...I feel very resistant, but I’ll use the law in my favour whenever I have to.” Like the activists who work with/within psychiatric institutions, their engagement with the MHCA is strategic rather than uncritical.

Finally, the lack of provisions for legal capacity is a big part of the opposition to and rejection of the MHCA by the mainstream psychosocial disability movement. The exalted position this provision holds for those with ‘mental illnesses’, is easily explained by the tangible effects of a denial of legal capacity. It snatches away important rights—the right to vote, the right to have autonomy over one’s body, the right to marry, the right to adopt, the right to inherit, the right to form associations (Davar, 2015c). Whatever one’s official/outward position on implementation and practicality, we understand legal capacity in our bones, it has the potential to return our personhood, and our humanness to us. The MHCA did not deliver this personhood to us, i.e., “capacity is still being asked and is still being evaluated” under it (*Laila*). From the singular frame of psychosocial disability, the MHCA was a failure, it denies legal capacity, continues to enable

guardianship, and hence must be disengaged with. However, some of my interviews presented a different viewpoint. Working and living as they do within an intersectional framing, some of my interlocutors pointed to a subtle, but critical, change in guardianship law i.e., one could choose one's guardian.

Our 'wonderful' family is being undermined by this Act because suddenly nominated representative can be anybody. It doesn't have to be next of kin. Next of kin, again, in law, be parents or marital family or origin family. (JJ)

The Mental Healthcare Act came out that has very radical understandings of...family. It has very queer radical understandings because those are the people who wrote it. (Falak)

For queer people with psychosocial disabilities, the guardianship provision while regressive in some ways, was radical in others—it acknowledged and reinforced the queer idea of chosen families. Within the context of India, a queer understanding of family also undermines the supremacy of 'blood relations' and starts to fracture the idea that "you only have love and respect for your caste families" (Shivangi Agrawal). Abolition vs reform vs disengagement cannot yield such an understanding, it is only through the work of *intersectional engagement*, one that comes from being involved in multiple movements and activisms, that my participants' analysis emerged. For the cis het Savarna subject of the mainstream psychosocial disability movements, the MHCA was a complete failure because of the continued existence of guardianship. For queer people who are not psychosocially disabled, the MHCA is seen as irrelevant to their lives. However, for the queer mad subject, the change in the guardianship provision is hugely impactful. Similarly, at the intersection of caste and psychosocial disability, the MHCA is another vehicle and sphere where Brahmanical supremacy can be undermined.

#### *Romanticisation of community and the turn to spirituality*

If the movement refuses to engage with psychiatry, and the mental health system at large, where then does it focus its energy, and what solutions to distress does it offer? The consequences of the disengagement position of the mainstream movement—the failure to address the concerns of marginalised communities and the active harm it can do to those communities—is most clearly seen in two arenas: one, an exclusive and limited focus on community inclusion; and two, an emphasis on spiritual, religious, and alternate ways of healing. Here too, an intersectional engagement with psychosocial disability, reveals the limits and harms caused by single-issue framework of the mainstream movement.

An “extensive engagement with the community” has always been part of the mission of Bapu Trust and the mainstream movement, but the exact parameters of what that looks like has shifted along with the movement’s engagement or the lack thereof with mental health systems. Their work started as a community mental health programme and focussed on raising awareness and building community-based mental health support. The majority of its work now is “to fulfil the obligation in Article 19 of the UNCRPD, which is the right to live independently in communities” (*Laila*) without a focus on or engagement with issues of deinstitutionalisation and/or access to affirmative mental health services. It is now entirely focussed on “how to get communities to include people and accepting difference and not placing difference as something that needs to be placed outside the community” (*Laila*). For others, however, community inclusion work is not separate or opposed to work on deinstitutionalisation. For *RP*, the question is “How do you create inclusive communities by deinstitutionalising people?” For her, the work of community inclusion includes:

By renting out homes in the community and we are enabling people from the mental hospital...to transition into the community independently... we are kind of increasing awareness and promoting inclusivity. So, we do a lot of events...within the community so the community is able to kind of see that these people are capable people...So we kind of balance both the community and these people. (*RP*)

When we work in our community, we work on their banking rights—we work on specifics like banking rights, working on all their entitlements and everything. (*RP*)

Despite this extensive and wide-ranging work with community, there is a significant gap in the work of the mainstream psychosocial disability movement—a lack of an analysis of what community is and how it functions in India. A singular focus on inclusion based on psychosocial disability fails to address exclusion on the basis of gender, queerness, religion, and caste. *RP* gives an important example of the difficulty of finding housing for a single woman within the ‘community’ emphasising that their work needed to address patriarchal attitudes as much as exclusionary attitudes towards psychosocial disabilities. However, there is little mention of caste and/or religion from the majority of the psychosocial disability organisations who work on community inclusion. Housing in particular, has long been inaccessible to those from DBA and Muslim backgrounds<sup>44</sup>. Within the charged atmosphere of Hindu nationalism, this has become

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<sup>44</sup> Muslims, Dalits, and people from North-East India are often denied rental houses due to discrimination, often perpetuated under the guise of wanting vegetarian tenants. Such practices of housing discrimination lead to

worse. As I was writing this section, in one of the many WhatsApp groups I am part of came this appeal: “A young Muslim woman I know is looking for a place to stay in [redacted city] [redacted date] and is struggling and facing a lot of Islamophobia. If there is any chance you can help find an appropriate place, please let me know.” A singular focus on disability erases the struggle of disabled Muslim or DBA or queer people. Even if all communities were disability-inclusive, without a focus on the intersectional mechanisms of exclusion, they would continue to exclude on the basis of caste and religion and would not include *all* disabled folks.

A second implication of disengagement with mental health has been a turn towards what we can call alternate or traditional practices of healing i.e., “let's yoga this out of ourselves” (*Falak*); a statement so common, it is a meme. I do not write this to debate the merits of whether or how any individual practice benefits an individual person. *Aman* puts it best:

I talk openly about the fact that I've tried ten different forms of therapy, including some modes of healing that my scientific friends will scoff at, including past life regression, including homeopathy, including shamanism. I have tried everything, and I feel nobody has the bloody right to shove their activism in the face of a person who just wants to stay alive... My problem is not with mindfulness. My problem is not with yoga. My problem is not with dance therapy...My problem is when these things are weaponised in an organised way. (*Aman*)

What does an organised/weaponised turn to spiritual healing practices look like and what does that mean for those harmed by it? *Chandra* describes their experiences with this type of weaponisation when they were an intern at a mainstream psychosocial disability organisation run by a prominent activist. One, there is a form of pill-shaming, a shaming of anyone who takes medication or accesses mental health services. Within the organisation they worked in, they experienced this sort of shaming for taking diabetes medication. Second, and complementing the pill-shaming, there is a pushing of what they term “toxic positivity” and “toxic spirituality”. They go on to describe their experiences:

But I really want to ask people sometimes when you go and tell people or when you make fun of people and...ridiculing people for accessing support. A lot of people do not have resources to be supporting themselves without say intervention from a therapist.  
*Matlab tumhare paas paise hain* [this means if you have money] you can go to a yoga retreat,

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residential segregation, particularly for Muslims in urban areas. For more information, refer to Sharma (2022) and Jaffrelot & Gayer (2012).

works for you, good for you. Like I think this is also upper caste privilege, right?

(Chandra)

One of the few senior activists still associated with the mainstream movement I interviewed spoke at length about a spiritual model of psychosocial disability and spoke about the temples as safe places where they could go and sit in peace without worry of harassment. It was a methodological moment of complexity for me. As a researcher, I felt the need to let them talk without challenge. On the other hand, as someone who aspires to embody anti-casteist politics I needed to intervene. I tried to interrupt them, perhaps too meekly, starting to say “But that is not...” but that interruption was not heeded or heard. It is here then that I must make my intervention.

Turns to spirituality/religion cannot be de-linked from the political context in India and there are two important points to be made here. First, there is unsaid prefix to spirituality/religion and within the Hindu nationalist context of India: a turn to spirituality is a turn to *Hindu* spirituality (at best it will include ‘non-controversial’ religions such as Buddhism or Jainism) (Mehta, 2017). And second, Hinduism is in itself the system of oppression for those from oppressed caste backgrounds (Ambedkar, 2013). *Bhanu Priya* highlights the challenge of doing anti-caste work within the disability movement:

Also, when the question of disability arises you will see that people are more spiritually and more religiously...So, coming from an anti-caste perspective, talking about dismantling this religious system within the disability rights movement is more of a challenge. (*Bhanu Priya*)

When we move away from the people who can afford yoga retreats and breaks from work; when we move away from Savarna folks who can walk into temples unaccosted; and when we move towards those oppressed by religious structures for generations; when we start to include those with highly distressing experiences, we can then begin to uncover that these ‘alternates’ are not liberatory but rather akin to jumping from the pot into the fire.

In the examples of deinstitutionalisation, mental health legislation, and the turn towards community and spirituality, a certain type of lived experience and positionality is centred at the exclusion and expense of other people. *SL* states that within the mainstream movement, “lived experiences that you see and hear mostly are going to be of upper caste people and the lived experience of people from various marginalised background are not understood as lived experiences.” The exclusions and marginalisations within the work of the psychosocial disability

movement follows the lines of exclusion in other realms of society, i.e., caste, religion, and class and intersectional ways of ‘doing’ psychosocial disability vis-à-vis psychiatry requires a nuanced, contextualised, and strategic approach.

### **5.1.3 Monolithic imaginaries: unsettling the imagined subjects of psychosocial disability**

But where are we going? What are we trying to work against? What are the systems that we have named that are problematic? (*Falak*)

In the arguments of mainstream psychosocial disability (and to an extent in my writing), psychiatry and all other mental health services are conflated. In this section, I unpack what we mean by psychiatry and what the landscape of mental health services is as well as who we understand as their subjects. Discarding the imagined homogeneity of mental health services and its subjects enables us to find pathways which both embody the abolitionist fight against harmful systems and are cognizant that people rely on these services to survive.

Beyond psychiatry, the ecosystem of mental healthcare in India includes practices of clinical psychology, psychotherapy, and counselling. It is a messy landscape comprising both therapeutic approaches stemming from biomedical frameworks as well as approaches founded on different therapeutic frameworks. Other scholars and researchers have argued that instead of singling out psychiatry, it is helpful to speak of the psy-sciences and the psy-complex. Without using this specific terminology, the early psychosocial disability was founded on the understanding that a cluster of practitioners (psychiatrists, psychologists, psychotherapists), practices (medication, individualised therapy, institutionalisation), and their underlying epistemology (biomedical model) require change.

*Aman* explained that the current mental healthcare landscape makes it hard to understand who is practicing what type of approach. They explain that this difficulty is because it is now “fashionable to say bio-psycho-social”, “taboo to say that your understanding of mental health is only biomedical”, and that everyone claims to be working with a bio-psycho-social approach only then to continue with their biomedical approach. Furthermore, he reminds us that the biomedical approach is supported by extensive psychiatric infrastructure.

We are hundreds of years away from that apparatus disappearing, that kind of thinking disappearing. But the posturing has changed, right? The harm continues to be present, and I think will haunt us for many, many years, of excessive reliance on biomedical thinking. But I think the language, I think a lot of people are queasy now to say biomedically. (*Aman*)

We're talking about it in just like really frustratingly semantic terms. You are missing the fact that, you know, the ye old historical asylum of the 1800s is happening right now here. That's the same thing. We have not decolonized the asylum in India yet. (*Falak*)

It is a messy changing landscape, and it is thus understandable to me that all forms of mental healthcare are painted with the same brush. However, this has real implications. Many of my interlocutors have trained as arts-based therapists (offered by Bapu Trust) or as Queer Affirmative Counsellors (offered by CREA<sup>45</sup>). Where do these sorts of affirmative and non-biomedical based practices and practitioners fit within the disengagement agenda? For *Roop*, a Dalit queer activist, affirmative care is progressive and is a place of reclaiming personhood. Other interlocutors mentioned the role of individual therapists who base their practice within structural causes of distress and speak in terms of oppression not illness. Can we then begin to break down the idea of mental health as a monolith and what happens when we do?

So, for Dalit person or for queer person who has been pathologised in a very different way, for them to also get access to the care in a very so-called affirmative way, it is very very so, is this another way of, you know oh, progressiveness. (*Roop*)

I have repeated the point that the 'abolish vs reform vs disengage' debate and the actions they enable and rely upon come from and speak to a particular subject location, one that is unspoken and unmarked in this debate. In India it formulates this subject as cishet Savarna middle class person who can *choose* to accept or decline mental health care. Disengagement with psy-sciences and practices is a rejection of mental healthcare. Puar (2017) asks us to think about how "populations who have little access to health [are] situated in this formulation?" (p. 74) Within psychosocial disability in India, how are those who have never been able to access any sort of healthcare, those whose personhood is erased or denied by society everywhere and not just within psychiatry, those who face neglect rather than overreach, represented within this formulation?

Okay. So, before that since you were talking about diagnosis, that's also, getting a diagnosis is also a privilege. So, a lot of people don't have access to the medical health system itself. (*Bhanu Priya*)

*Roop* presented the idea of access to healthcare as a radical political act. Coming from a Dalit queer background and active in both these movements as well as the psychosocial disability

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<sup>45</sup> Website for CREA: <https://creaworld.org/>



movement, they put forth that for those, like themselves, who are denied medical care or any institutional care at all, access to systems of care including medication and mental health care is a political act. The acknowledgement of their bodymind as something to be cared for and the validation of their pain by an establishment, is itself a political act. Psychiatry here becomes a place of bestowal of personhood rather than its removal.

But for me to go and get access by a doctor and doctor paying me attention is a new thing because I never had it. I remember as a child I was just another poor child to the doctor you know, like just *jisko koi bhi dawai de do, uski mummy ko kuchh pata nahin hain* [just give him any medicine, their mother won't know the difference]... You know when people say it '*ke app toh dawaai le rahe ho, yeh kar rahe ho, woh kar rahe hain*' [you are taking medication, you are doing this or that], first of all I feel if it's like the context really matters, that who is taking the medication. (Roop)

These debates of anti-psychiatry<sup>46</sup> and everything and I'm like either I choose to die today to be a very radical anti-psychiatric person. And I am like that also won't matter because I'll be this another number who will die only... As Dalit person, as queer people, we did not even had access to the medicine. And I am like for us also taking medication is also very political. You know, because I know that as my own identity as a Dalit person, like for us to afford medicine is a huge thing. You know that doctor is giving me attention. (Roop)

Finally, while these debates are strategies for activism, fodder for research, and the content of much discussion, they are also the lived realities of the people I interviewed. The stakes of reductionist or universalist thinking are life and death.

So, you know that that debate with antipsychiatry like you're not radical enough *arre*, but like, what do you want me to kill myself? (Roop)

It was made clear to me by my participants, and I know this in my gut from my experience, that in the absence of any other mode of care, we both need psychiatry and need to change/dismantle it.

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<sup>46</sup> The relationship between anti-psychiatry movements (led largely by psychiatrists and clinical psychologists) and the user/survivor movement is contested. Some see the user/survivor movement, especially its abolition focussed branches, as a descendent of the radical anti-psychiatry movements of the 1960s. Roop in this quote is referring to all parts of the user/survivor/psychosocial disability movement which see no utility in or use for mental healthcare. This includes the disengagement contingent of the psychosocial disability movement.

So, it feels like we are juggling both being in a community that is critical of the medical community, which I am also, but also needing to interact with the medical community to continue existing in the world, right? And that tension is not a tension that seems to be resolving anytime soon, right? (*Neba*)

In conclusion, the psychosocial disability debate in relation to psychiatry has been framed by ‘abolition vs reform vs disengagement’ and the mainstream psychosocial disability movement in India has largely chosen to disengage with mental health institutions and laws. However, the very terms of this debate and the choices made by mainstream movement leaders have neglected to employ an intersectional lens and hence excluded the concerns and lives of those who live at the intersection of multiple oppressions. To ‘do’ psychosocial disability in a way that is liberatory for *all*, the movement needs to orient to multiple dimensions of exclusion simultaneously. My interlocutors provide a critique of the current disengagement position of the mainstream psychosocial disability movement and provide examples of their strategic engagements with psychiatry. Their engagement is not an uncritical acceptance of psychiatry but rather acknowledges its harms and the need to mitigate them and at the same time the material and structural realities which require people to access psychiatry. In this way, psychosocial disability is ‘done’ by my interlocutors in ways that espouse an abolitionist critique of psychiatry contextualised to and mediated by the material realities.

## **5.2 Psychosocial disability and human rights: the limitations and failures of disability rights**

CRPD and a human rights approach, I think that's quite important in a context like India, where rights are a pathway, entry way to access benefits and so, rights-based legislation is literally the first step. At the same time, rights cannot be the end of the journey, it really cannot be... unless we address class, caste, communalism, fascism, militarism, war we cannot that, there's no point in human rights. (*Tara*)

The disengagement with psychiatry as part of the mainstream psychosocial disability movement’s agenda was accompanied by an embrace of disability rights. The idea that human rights or rights-based approaches are central to psychosocial disability is so ubiquitous that none of my interviewees said it explicitly despite referring often to disability rights, human rights, rights-based approaches/paradigms, and specific rights-based legislations. I understand this non-saying, this silence, as an implicit understanding between me and my interlocutors that a move towards human rights is a key part of how psychosocial disability activism came to be. Their explicit references to human rights peppered throughout the interviews are a testament to how much

they continue to influence psychosocial disability activism. In this section, I look at how disability rights (in the form of national legislation and the UNCRPD), the state, and human rights discourses are positioned in the work and words of my participants. I ask and answer questions about the kinds of practices and actions prioritised by a disability rights framing, whose interests they push forward, and what issues and solutions that are left behind. I argue that an intersectional engagement with disability rights reveals the problematics of a state-centred human rights approach for multiply marginalised communities. Centring a Savarna subject of disability rights obscures the role of state violence in creating distress and disability and subsequently narrows what constitutes psychosocial disability activism as well as who can be considered psychosocially disabled.

The literature and my interviews highlight the primacy of the UNCRPD in setting the tone for psychosocial disability movements. The UNCRPD came into existence through the efforts of Mexican disability activists who wanted a UN convention that focused on the rights of persons with disabilities. The group central to drafting the UNCRPD, not only included global South representatives, but was led by them. Psychosocial disability's validity as a Southern concept, as a Southern framework is thus tied to how we understand the UNCRPD. Participants spoke of a 'pre' and 'post' UNCRPD, dividing the psychosocial disability movement into eras marked by the UNCRPD in 2006. All my participants regardless of when they came to psychosocial disability point to it as key in creating the concept, identity, and movement of psychosocial disability in the global South. The UNCRPD, as a UN instrument, embodies a specific understanding of human rights originating from the Universal Declaration of Human Rights. This has permeated how human rights are understood within psychosocial disability movements and continues to shape how psychosocial disability is 'done' in regard to human rights institutions and discourses (Meekosha & Soldatic, 2011).

### **5.2.1 Flaws and/or features of disability rights legislation**

The need for, and engagement with, disability rights legislation was a repeated theme in my interviews. Most participants spoke at length about their critiques of disability rights legislation, the RPD Act, in India. Through their intersectional analysis, my interlocutors also interrogate whose interests are furthered through disability and other legislation, as well as the role of the state within disability rights discourses. Building on my interlocutors' analysis, I argue that the limitations of disability legislation can be understood as not just flaws but its features, i.e., the system does not fail to protect people because it is broken, but rather it is working as designed

and was never intended to protect people. This is a key idea in abolitionist thought and is reflected in at least some of my interlocutor's work (Shehk, 2021).

### *Why we need it?*

My interlocutors offer several reasons for the centrality of rights-based discourse within disability legislation. First, people with psychosocial disabilities, and disabled people more generally, have been at the receiving end of violence and abuse from institutions like schools and hospitals as well as from families and society at large. Legislation, flawed as it may be, can provide some level of protection. Even in the absence of full implementation of a legislation, its existence itself can be used to mobilise change in attitudes and practices of communities and people. This is particularly so within a context where the state is perceived as a site of violence and bureaucratic entanglement with it is to be avoided.

If you just mention [the law], you don't have to push, file a case, just go and say it 'what you doing is discrimination'...if you just say that this is against law...And we have seen many such cases where once you say it's what you're doing is illegal, they stopped.

*(Shampa Sengupta)*

Second, for persons with psychosocial disabilities who have long been rendered as non-persons within the law, institutional recognition is a significant victory (Davar, 2015c). *Shampa Sengupta* reminds us that in the absence of that recognition "we were just not there for the government." *Aman* described that the inclusion of rights of people with mental ill-health within political parties' campaign manifestos "was a huge moment for us because there was a recognition that these people are also voters".

Finally, disability rights legislation is a key pathway to access benefits and entitlements. *RP*, when describing her work on human rights at the community level emphasised that it was centred on getting "banking rights" and "entitlements". Ghosh (2016) explains that at the grassroots level human rights "are interpreted as entitlements and schemes framed by either central or state government for persons with disabilities" (p. 191). Within the material context of discrimination and exclusion, the RPD Act can be a lifeline to alleviate or mitigate the poverty faced by many disabled people.

It is therefore no surprise that many, if not most, of my participants engaged with the UNCRPD, MHCA, and the RPD Act extensively—they took part in consultations on the draft bills in the mid-2010s; they work with stakeholders to increase awareness; they demand the state fulfil its obligations under the UNCRPD; they write policy papers and opinions; they take on individual

cases for advocacy. However, as is the case with their engagements with psychiatry, this is not an uncritical endorsement of the specific laws or the utility of human rights at all.

### *The flaws*

My interlocutors offer three main critiques of the RPD Act, as well as legislation more broadly, many which are well-documented within the literature—the disconnect between international mechanisms like the UNCRPD and everyday life; the lack of implementation of national legislation i.e., RPD Act; the discord between the explicitly stated rights-based approach and the continued use of both the charity and the medical model within the RPD Act (Dhanda, 2018; Meekosha & Soldatic, 2011). In addition to these founded concerns with the RPD Act, my participants draw on their experience to unpack how the RPD Act functions as a tool of the state and for what purposes.

First, the UNCRPD, although hailed as a central part of the discourse of disability rights and the impetus to reform national disability laws in alignment with its principles, remains distant from people's everyday lives. Disability scholars and activists globally have pointed out that for most people the idea of challenging human rights violations through UN mechanisms is an alien and alienating concept (Meekosha & Soldatic, 2011). The barriers to any such process are so high that its existence comes to mean nothing. *Anita*, who lives and works in the heavily militarised area of North-East India, says:

I feel like 80-90% of the people in the Northeast don't even know or don't even care that India has ratified the UNCRPD. And why would they? How does it come into their real lives and their daily lives? (*Anita*)

A second key concern is the lack of meaningful implementation of the RPD Act and any legislation more broadly.<sup>47</sup> As the saying goes “there is the law and then there is life”, meaning that the existence of a law does not necessarily mean that it will be implemented. The state's neglect is so widespread, that participants convey it as a commonly understood truth, and I had to prompt them for specific examples. Furthermore, efforts at implementation of the legislation are often partial and haphazard leading to unintended consequences. For instance,

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<sup>47</sup> This critique is not limited to the RPD Act. *Roop* and others make similar critiques—they didn't go far enough to ensure rights; they were badly implemented; the processes were bureaucratic—about other pieces of legislation. “...because even we have SC/ST Act, we have 377 vanished away, we have Trans Rights Act, but the [lack of] implementation is scary.” (*Roop*)

...there is a Supreme Court order which says that you cannot hold people inside the mental hospital for several years...So what is happening is mental hospitals are sending them to different homes, which probably is closer to their hometown. But one of the clients with me, she says that the place where she was shifted to, it was a very tiny space which held ten beds and suffocating. And there was a little bit of sexual abuse and stuff like that happening, so she was very scared...So it's very easy to put a law saying, "Don't do this. Do this," but does it really benefit the person? (RP)<sup>48</sup>

This haphazard decision making and implementation has broader epistemic implications. For instance, in the aftermath of the Erwadi fire at a faith healing centre which killed 28 people, the state targeted *all* faith healing centre, closing off avenues to non-medical practices, but also in time, non-medical *understandings* of mental (ill)health (Basu, 2009; Kalathil, 2007).

Finally, the RPD Act was supposed to embrace a human rights framing of disability, moving away from a charity and welfare model tied to medical categories. However, the Act is still shaped as "a legislative and judicial structure based upon "compensatory discrimination" that includes specific quotas for specific diagnostic labels" (Friedner et al., 2018, para. 6). For my participants, the dominant part of the RPD Act, both in terms of the Act itself but also in terms of how it is understood and actioned, has to do with benefits and welfare based on a medical assessment of impairment.

There's this whole issue of being certified to be able to get the accommodations or benefits that the state is supposedly providing. And you have to be a certain threshold. And I'm like, "My goodness." Like now you have to actually get a quantified measure of [laughs] of your identity. It's still so medical... how do you even quantify some of these things? (Sanya)

Sanya is referring to the requirement of proving yourself to be 40% impaired to be eligible for disability benefits. For people with psychosocial disability, not only is there no clear sense of what 40% psychosocial impairment would be or how it would be quantified, it must also be assessed by a psychiatrist. And even for those who are willing to go through this medicalised and dehumanising process, Shivangi Agrawal tells us "they're told that they're lying, or they're told that it's not a disability" by the bureaucrats in charge of issuing a disability certificate. A reformist

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<sup>48</sup> This is eerily similar to the Life Esidimeni tragedy in South Africa, where at least 144 people died in the months following a quick and haphazard mass transfer of institutionalised patients to smaller care centres, many of which were later found to be fraudulent. For more information: <https://section27.org.za/campaigns/life-esidimeni/>

reform approach here would be to improve the text and implementation of the RPD Act, a view that is espoused by many within the mainstream disability movement in India. However, my interlocutors employ a more radical understanding of the RPD Act.

### *The features*

In contrast to understanding the shortcomings of the RPD Act as oversights or issues of implementation, some of my participants embraced an abolitionist reading i.e., the shortcomings of the Act are its features. In other words, the flaws of the Act which make it incredibly difficult for disabled people to access benefits under it are not a bug, rather a feature designed to limit the number of people accessing it. *Shivangi Agrawal* critiqued the bureaucratic nature of the mechanisms set up for its implementation and the “long process” of bringing anything to the government’s attention saying that the RPD Act is an “irrelevant document... and it’s not something which is about our daily lives at all. It’s just a fantasy”. *Sanya* pointed to the long list of new disabilities included in the Act and stated that the RPD Act was not designed to be “implementable”.

The way they went about operationalising it, you realise there’s absolutely zero kind of understanding of what each of those disabilities meant in terms of a state’s responsibility and accountability towards delivering on something. It was almost like this kind of a laundry list, and then you just continue. (*Sanya*)

Friedner et al. (2018) argue that the very category of cross-disability as conceptualised under the RPD Act actually works to undermine a strong cross-disability movement. Beyond the tensions which arose from differing needs of different impairment groups, as I outlined in Chapter II, the benefits under RPD Act are not distributed equally across all disability constituencies but rather differentiated according to impairment type. For instance, the 5% reservation in employment for disabled people are then further divided unevenly between the 22 recognised disability groups. This creates a zero-sum game, wherein any new disability constituency must compete with other disability constituencies for limited resources. In a very real way, any material benefit extended to one group of disabled people comes at the expense of another. It is obvious that this leads to a cross-disability movement that is not united. In this way, the RPD Act, supposedly a piece of legislation based on the UNCRPD’s disability rights-based approach, actively hinders the possibilities of a strong disability movement in India and has a particularly deleterious impact on the inclusion of ‘newer’ disability categories such as psychosocial disability into the disability movement. This issue was pointed out by my participants, with one framing the problem as a feature of the law, not a flaw.

Finally, two participants questioned the intentions of the state. As *Roop* puts it “the state has never protected me, it only protects itself”. *Shampa Sengupta* describes the (mis)use of a specific provision of the RPD Act which requires the registration of all NGOs providing services to disabled people. This provision is, arguably, in place to protect disabled persons from fraudulent or harmful organisations. However, in her experience, it links the survival of an organisation to government approval. This subsequently has a chilling effect on a disability organisation’s potential critique of government policy. The legal provision claiming to protect disabled persons is implemented in a way that actually protects the state at the expense of disabled persons. For my participants, legislation, even rights-based legislation, cannot then be relied upon for radical or even any significant change in the status quo.

I had been questioned by Disability Commissioner 's office many times, that you are not registered how can you work on this? And I said I don't give service to disabled people so we're only advocacy groups. And you know the moment you become a service giving organization, it becomes very difficult for them to fight for rights because you are depending on the government for your whole recognition...for example, Mano Vikas Kendra, it's a big NGO, they're doing good work. Suddenly the government of West Bengal said your registration is withdrawn, they have to stop all the work ...so they have to keep a good relationship with government always and for us the people from the movement we keep on questioning the government... (*Shampa Sengupta*)

This type of state excess is of particular relevance in the current political climate in India and for almost all of my interlocutors who occupy multiple marginalised locations. My interlocutors are aware and even wary of the problems and potential of disability rights legislation. They ‘do’ psychosocial disability with the knowledge that neither the RPD Act nor the state will provide justice but can still be leveraged in certain circumstances towards specific goals.

### **5.2.2 Beyond *disability rights* and beyond disability *rights***

If I had interviewed just the mainstream psychosocial disability movement actors, perhaps the section on disability rights would have concluded here. However, as my participants hail from intersectional movements, their understanding, actioning, and critique of human rights go beyond disability rights and include laws and legislations linked to other aspects of social justice. My participants expressed both a need for and a frustration with the lack of intersectionality in the mainstream psychosocial disability movement as well as the other movements they engage with. I argue that the lack of intersectionality further entrenches the imagined subject position of



psychosocial disability and fixes the boundaries of that category at the expense of those who do not fit it.

First, my interlocutors mention many examples of the laws and legislation which govern their lives and shape their work—the Transgender Persons (Protection of Rights) Act 2019, passed after much debate within the trans activist community; the Scheduled Caste and Scheduled Tribe (Prevention of Atrocities) Act 1989, meant to protect DBA communities from caste-based violence; criminal penal codes related to violence against women; Armed Forces (Special Powers) Act 1958, a horrifying act employed in North-East India that enables human rights violations by granting special powers to the Indian Armed Forces; the Constitution and the rights enshrined in it; the Islamophobic and exclusionary Citizenship (Amendment) Act 2019; the abrogation of Article 370 of the Constitution which completed the process of annexation of Kashmir; the repeal of Section 377, the colonial sodomy law which was in place till 2014; legislation related to reproductive justice and abortion. Some of the above protect the rights of Indian citizens, some take away rights from citizens, and some put the very question of ‘citizen’ into question.

My interlocutors’ lives, many of whom are trans, queer, Muslim, Dalit, are governed by more than disability legislation and they provide examples of the work they have done with these other areas of law and legislation. *Bhanu Priya*, who runs an DBA disability collective, ensures that their work reflects its diverse membership.

We started with trainings on social movement history and legal trainings. So, our intention was to have the group as entirely intersectional. So, there are queer folks within the group, there are trans folks within the groups, there are women in the group, there are also men. So, we ensure that we are a diverse group...So the legal training involved training on the SC/ST Atrocities and the Trans Rights Act, the PWD Act, Persons with Disability Act. (*Bhanu Priya*)

Other participants mentioned being part of consultations, strategic litigation, and other types of advocacies in relation to queer rights, trans rights, women’s rights, and labour rights as well trying to build bridges between these movements and disability activism. *Naina* describes a beautiful, albeit ultimately short-lived, example of cross-movement solidarity.

We had kind of that solidarity between the trans movement and the mental health movement in Chennai, especially after the NALSA judgment when the law came in and

this is psychiatrists need to sign off on people before they transition.<sup>49</sup> And, you know, it was really like, “Hey!” You know, the whole idea of shrinks, gatekeeping, etc, was really something that we were very closely looking at together. (*Naina*)

*Naina*, echoing many other participants, went on to say that this was a brief and out of the ordinary encounter and for the most part the disability movement works in a silo. Interlocutors were explicit that the mainstream movement did not want to discuss or action anything they deemed ‘political’ and the definition of political was very broad when it came to identities and issues other than disability. Some attributed this to the very real consequences of seeming ‘political’ in fascist times and the narrowing list of issues that can be safely addressed. However, others pointed out that this reluctance is more sinister, stating that “there are a lot of right wingers within the disability rights movement”. In other words, and within the context of a violent Hindu nationalist government, there are people within the movement who are fighting for disability rights and at the same time tolerate or support violations of human rights of religious minorities, oppressed caste communities, queer people and other targeted groups. I will further explore this dynamic of the movement in the next chapter. Bringing back the role of the state in maintaining this siloed way of working, *Roop* posits that it is the state which wants you to choose one identity over another, especially when it comes to exercising your right to reservations.

“*Woh issue aa jaenge aur uppar se... Woh [the government] sirf ek cheez ka dena chahte hain, main bata rahi hoon, ya toh aap disabled ho, ya aap queer ho, ya aap trans ho, ya aap ho Dalit ho. [That issue comes from above, they [the government] just want to give you benefits/reservations related to one thing, either you are disabled, or you are queer, or you are Dalit].* (*Roop*)

A second key point of concern for some of my participants is the relationship between disability rights, marginalised folks, and the state, particularly the limits of disability rights, indeed human rights, when the state ignores, condones, enables, and/or perpetuates marginalisation. Within the current political context in India, the state is complicit in creating, or at least promoting, violent and discriminatory social and legal conditions for people and communities marginalised for their

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<sup>49</sup> NALSA refers to the 2014 Supreme Court case *NALSA v India* which ruled that transgender people as a marginalised group are entitled to benefits in education and employment and critically, can self-identify to get these protections. However, the Transgender Persons (Protection of Rights) Act 2019 undermines these protections and requires transgender persons to undergo a lengthy and invasive medical certification process (including surgery) to be recognised as transpersons. The Act was widely criticised by queer and human rights activists. For more information, refer to Knight (2019), Kumar (2021), and Vidya (2018).

religious locations. The disabled amongst these groups are unlikely to benefit from rights-driven disability activism. For most of my participants who live at the intersection of several contemporary and historical marginalisations, they are cautious of, if not totally mistrustful of, the state and its mechanisms. JJ gives an example:

When it comes to psychosocial disability, there's that whole question of, as a Muslim person, what is going to be my relationship with state. I'm probably not going to be able to go to state even for asking for welfare. Because state has been such a perpetrator in my life that I may not be able to even go for most benign sounding, whatever ration card and whatever those kinds of issues that might be there. (JJ)

The perception of the state as “benevolent, and sparing, and caring, and maybe giving of grace or justice in some way” as is the case within mainstream disability rights is just not true for those living at multiple marginalities (Ben-Moshe & Harris, 2023, 36:01). Making disability rights the lynchpin of how one ‘does’ psychosocial disability leaves those people behind. More than that, this framing obscures state complicity in causing and creating distress and disability. The most straightforward example of the state creating disability and impairment in the Indian context are the tactics used in Indian-occupied Kashmir such as the use of pellet guns which has resulted in multiple instances of blinding (Zia, 2019)<sup>50</sup>. Less visible and tangible, but equally impactful, is the distress caused by the campaign of terror against Muslims in India. Within this context, the state cannot be relied upon to address the distress caused by its own excesses.

In summary, the mainstream psychosocial disability movement's reliance on disability rights creates a cycle of exclusion and siloing. Disability rights in the form of the RPD Act can only address certain types of disablement i.e., the medically certifiable non-politicised distress/alternate states of being. These forms of distress then come to define what psychosocial disability is and those who fit that category are framed as the main constituency and leadership of the movement. The marginalisations which this narrow category of psychosocially disabled people face can be mitigated (to an extent) through strengthening disability rights protections which then further embeds disability rights as the mainstream movement's main focus. Issues that are less legible as psychosocial disability—like the disablement of religious minorities, DBA communities, trans and queer folks—must then be addressed elsewhere. In this way, the

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<sup>50</sup> Starting in 2010, the government of India started using pellet guns as a means of crowd control in Kashmir. Supposedly a nonlethal weapon, pellet guns have caused deaths, injuries, and most notably eye injuries leading to blindness. After the abrogation of Section 370, the use of such weapons escalated dramatically, leading many activists and scholars to speak out against the brutality of such measures. For more, refer to Ather Zia's (2019) article on the use of pellet guns in Kashmir using the analytic of Puar's (2017) ‘right to maim’.

normalisation of some disabled bodies and minds through inclusion within the legislative framework and within the movement itself, works to exclude others from disability identities and protections, but importantly does not exclude them from disablement itself (Puar, 2017). Despite these limitations, the people who embody these socio-political locations and work within the movements which focus on them, do still engage with disability rights.

### **5.2.3 On the margins of disability rights: systemic analyses and strategic engagements**

My interlocutors engage with disability rights despite all the flaws and shortcomings of disability rights—lack of implementation and implementability, the harmful consequences of the ways in which the RPD Act is structured, its inability to address state violence and complicity, and the exclusion of multiply marginalised communities from its remit. They use disability rights strategically to further their larger radical aims, employing them as tools, making compromises, and finding loopholes and openings. In this way, they are re-framing and re-formulating what human rights mean to disability movements. First, my interlocutors provide examples of understanding and ‘doing’ psychosocial disability rights as a tool to bring about larger societal change, i.e., understanding the problem not in terms of individual rights or lack thereof, but rather a larger systemic problem requiring systemic change. Second, they describe the use of rights legislation and mechanisms strategically to push forward their agenda. While this work can resemble radical reformism, there is no set blueprint for it and my interlocutors often make uncomfortable compromises.

A key part of using human rights as a tool (as opposed to a goal) is the identification of the issues which create marginalisation and exclusion of persons with psychosocial disabilities. In line with their questions about the relevance of the law to everyday life, my interlocutors are clear that the issues they are facing are a part of a larger system of oppression.

I do think that the focus on rights as something to have doesn’t allow for the contradictions of systems to emerge. Like sometimes I feel like we’re not working at the level of systems, we’re working at the level of getting everybody their rights. I think while it is required at some level, I think.... systems are far more complex, and I think we need to also engage [that]...it’s not just a demand for something, but it’s like working to change that system as well. (*Laila*)

It’s like the law changes nothing if you don’t have the other enabling things around it. (*Naina*)

Many interlocutors implicate capitalism in creating and perpetuating inequality and injustice. Some go further and explicitly state that a “capitalist setup and a feudalist one” (*Raya*) creates a state of affairs wherein people are unable to access basic things such as food and clean water, and that within that system, human rights are irrelevant. *Laila* suggests that the use of human rights is akin short-term solutions used to alleviate poverty:

You can’t talk about poverty and then say that “we need to give people more stuff,” because that’s not going to address the question of poverty itself. That’s just going to say that a few people will get some things as assets at this point in time. Poverty is not going to disappear. Similarly, a lot of other systems need to be engaged with. It cannot be only about rights, is what I would say at this point. (*Laila*)

Despite these limitations, for *Raya* and others, human rights can be used as a tool for politicisation. *Raya* works within the labour movement and describes how “capitalist set-ups have been able to ingrain so much injustice in people” and how people have internalised a feeling of “*Yeh toh hamari kismat hain, hum mehnat karenge toh humko milega* [this is just our fate, we need to work harder to get anything]”. For *Raya*, talking about human rights in her work as a labour organiser and community mobiliser becomes a starting point to shift this thinking and get people to think about holding governments accountable for the conditions of their lives. Similarly, *Laila* describes using human rights and UNCRPD training to bring issues of autonomy, respect, and violence into the thinking and parlance of medical professionals who are often the perpetrators of rights abuses.

It is also creating a dissonance in the person...I have to now think about what I’m doing and really be conscious that if I am, like, overstepping somebody else’s right. So, I think even if one doesn’t fully buy into the idea of the right of persons with disabilities, they are still forced to think about it. (*Laila*)

A second, and related way that my interlocutors describe using human rights is by leveraging the mechanisms embedded within the UNCRPD and national legislation to draw attention to issues that would otherwise not be considered as within their remit. Two participants described how they used the mechanism of country shadow reporting—submitting an NGO-led report on UNCRPD implementation to the UN Committee—to address disability in Kashmir, a topic which is considered ‘too political’, divisive, and ‘anti-national’ by the disability movement in India.

I think some channels have opened, for instance in the last CRPD submission from the Women Disability Network, if you see the submission they have this thing around pellet guns and mental health and Kashmir, which I think is a big move for the disability movement in India 'cause they don't go that political... There is, like I said, there are some pathways that are opening, like tiny tiny pathways here or there where people are talking about this, but the movement as such I don't think has had a moment of reckoning at all. (*Tara*)

The moment National Platform sent this statement [about Kashmir], they [the disability movement] were like we shouldn't be talking about this, this is something not accepted, like anti-national, like the typical kind of thing starts. For us, like how do we talk about mental health or even think of the pellet victims who are losing their eyesight? Also, the riot victims, we had a riot where acid were thrown and so people losing eyesight and such and how can we do disability rights work while saying that this is not my work. So, people are like more “OK we'll do rehabilitation”, but we will not question the reason why this person became blind, why this person is losing a limb or something like that.” (*Shampa Sengupta*)

These are “tiny pathways”, as emphasised by *Tara*, on a distant, Northern, international forum. They are either ignored or actively opposed by the national disability movement. In contradiction to the mainstream psychosocial disability movement's assertion that the UNCRPD should be embraced as a Southern instrument, *Shampa Sengupta* positions it as a North-based instrument. In a weird way, the UNCRPD's existence as a Northern/Western instrument can and is used within India by some activists despite their own postcolonial critique of it or perhaps because of it. They recognise that it has a specific form of power as a Western instrument in the minds of people and governments. It is positioned as progressive, something to aspire to, important because of its coloniality, and that this can be leveraged to push through their demands by appealing to this colonial ideology.

Somehow, I feel that in India if something gets endorsed by international sector, people give more. People were not talking about women with disability until CRPD talked about it. Now the UN has said so, so all the disability groups have in their meetings have one section on women with disability. (*Shampa Sengupta*)

This is an uncomfortable thing, for me and *Shampa Sengupta*. We laughed awkwardly about it, it feels a bit dirty, far away from the ideological purity associated with activism. We might not speak of this type of tactic openly, but it is by no means an exception. I remember during a

meeting with Rwandan disability activists in Kigali, a person from the National Organisation of Users and Survivors of Psychiatry Rwanda (NOUSPR)<sup>51</sup> telling me that a part of their strategy was to leverage colonial hangovers of white supremacy in their work. Part of their fundraising efforts was arranging tours to villages and particularly to communities of disabled folks for tourists looking for an ‘authentic’ African experience. Association with white tourists (welcoming them into your home, eating with them, having them buy your handicrafts) bestowed upon disabled folks a sort of legitimisation within their communities. In this way, they leveraged the colonial mindsets of white visitors and tourists as well as Rwandan/Rwandese people to further their goals. I cringe as I write this because it is both brilliant and deeply uncomfortable. Both examples sound a bit like “through any means possible” but also “making oppressive structures work for you”. I don’t know where I land on this but, it is a thing, and an effective one.

The strategic and ideologically ‘impure’ ways in which human rights can be used as a tool to effect change brings about difficult questions around compromise, complicity, and co-option. Does leveraging the colonial hangover as in the example above embed it further? Do short-term gains come at the expense of the long-term fight for justice? These are questions that are alive in my interlocutors’ minds. *Sanya* asks what it means to negotiate with the state and state power—“what do you yield by going to the state to ask for certain things and what do you get in return”, adding later:

In some ways it’s remarkable that some of these people who led on the C 20 track<sup>52</sup>, particularly on disability, managed to have all these declarations and these high-level commitments on disability inclusion. But at what cost, I keep thinking, right? Like who are you meeting with? I mean, here is this government, which is literally lynching, at least supportive of, if not enabling them...And then to what extent are we going to be blinkered and say, “Okay, my issue I’m getting traction, so let me just move ahead”...Because, you know, we are going in with this really narrow sense of we’ll get a win, but whereas we know all around us there are people who will never have the opportunity right now with what’s going on. So, I feel even that, this sort of, this co-option I think worries me a lot, you know? (*Sanya*)

This discomfort, this constant worry, and challenging oneself, is a key part of strategic use of any tool or discourse. It stems from the knowledge that human rights and the state can be used to

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<sup>51</sup> NOUSPR website: <https://nouspr.rw/>

<sup>52</sup> C 20 refers to the civil society track of the G 20 Summit held in India in 2023.

bring about *some* change but will not be able to provide *the* change we need for justice-based goals. For the mainstream psychosocial disability movement, disability rights are the endpoint. My interlocutors will and do use disability rights but how they do so depend on the context and the specific demands within that context.

This entire section on how psychosocial disability is ‘done’ vis-à-vis human rights is founded on an understanding of rights as originating from the state. I probed several times for examples of human rights work which decentred the state and received either confused silence or once an assertion that “that it’s a privileged position to decentre the state” (JJ). Sumi Madhok (2021) in her work on vernacular rights cultures highlights how subaltern political struggles challenge the story of rights as emerging from the West and the nation-state. She gives the example of the concept of *haq* which employs other understandings of human rights. For the most part, my interlocutors’ critiques, analyses, and uses of human rights do not venture far from the top-down legal frameworks of human rights. My interlocutors however marginalised, came into being as psychosocially disabled within a UNCRPD understanding of human rights and as such, speak of them within that specific understanding. A different entry point and framing (such as madness or a non-English word instead of psychosocial disability) within subaltern or decolonial struggles would have yielded a different analysis of disability rights and human rights more broadly.

In conclusion, my interlocutors conceptualise and do disability rights beyond the RPD Act and the UNCRPD and look at the broader role of laws and legislation in the lives of people. This results in, and is a result of, their engagement with both life/rights limiting and supposedly life/rights enabling legislation. For them, what disability rights legislation can enable and for whom is connected to a myriad of other laws. This analysis enables the inclusion of those affected by non-disability related legislation into the remit of ‘doing’ psychosocial disability. It also opens pathways to strategically use rights and legislation if and when it can be to further their intersectional goals. The work they do is “critical of the state while also ensuring that the services that people need to stay alive remain intact or improved” (Sandoval, 2017, p. 52).

### **5.3 Discussion and conclusion**

In summary, psychiatry and disability rights have been central to psychosocial disability activism since its conception despite the movement’s shifting relationship to these institutions and the discourses which underlie them. For the mainstream psychosocial disability movement, psychosocial disability enabled a third option to the abolition vs reform of psychiatry debate which consumed the user/survivor movement in the global North—disengagement with psychiatry. Concurrently, the movement embraced a closer relationship with disability rights,



making them the lynchpin of the movement's goals. In other words, the violence of psychiatry and human rights abuses were to be addressed by disengaging with psychiatry and advocating for full inclusion into rights-based disability legislation. While this was framed as the universal solution to the problems that people with psychosocial disability face, my interlocutors trouble this assumption by using an intersectional lens. When the privileged unmarked subject (cishet Savarna) of these debates is named and acknowledged, cracks appear within the position of the mainstream movement.

For the mainstream movement, psychiatry is poison, and the state is medicine, but for my interlocutors living and working at the intersections of multiple oppressive systems, both psychiatry as well as the state are both the poison and the medicine (Niharika Pandit, personal communication, December 29, 2024). Hence, ideologically pure positions of abolition of psychiatry or its reform; abolition of the state or reform of disability rights law; or disengagement with either or both are not tenable. The question they are navigating is one that Puar (2017) poses:

how do people who rely on accessing significant resources within a political economic context, where the possessive individual is the basis for the rights claim—including the right to medical care—disrupt the very models on which they depend? (p. 35)

My findings highlight four key themes which are central to the work of my interlocutors. First, they mark the subject of the debates within psychosocial disability movement/activism and hence work towards changing the terms of the debates. Second, they use a systemic and intersectional lens to understand the issues of psychiatry and disability rights. Third, they undertake strategic engagements with these institutions, espousing elements of non-reformist reform. Finally, this work is not without complication or contradictions, and my interlocutors are consistently aware of that.

First, my interlocutors are explicit about the fact that disengagement with psychiatry and a complete reliance on state-given rights is a goal that can only protect a particular set of people with psychosocial disabilities who are normative in all other ways. For instance, disengagement fails the people whose lives are governed by mental health legislation, i.e., those without the resources to escape psychiatry and access alternative modes of healing. Similarly, for those who are targeted by state violence, especially within the context of the current fascist government, the state cannot be relied upon to provide protection from human rights abuses. By incorporating an analysis of the material conditions of people's lives and the multitude of axes of oppression they face, the very act of naming the assumptions behind the mainstream psychosocial disability

movement is an act of intersectional work. Implicit in the assertions of my interlocutors is a critique of the leadership of the mainstream movement as well as a demand for ‘doing’ psychosocial disability in ways which can be liberatory for *all* people with psychosocial disabilities.

Second, and related to the work of troubling the assumptions of a cishet Savarna subject of these debates, is my interlocutors’ insistence on a systemic analysis wherein each system of oppression is intricately connected and dependent on other systems. Their critiques of the systems and structures which govern us, the psychosocially disabled, are not simply for the sake of critique, but they are generative, nuanced, and transparent. They raise questions about the current state of psychosocial disability and provide an invitation to broaden our ways of ‘doing’ psychosocial disability and navigating the contradictions presented by the whole system. For instance, the analysis and work of my interlocutors implicate the role of the larger system of “capitalism and feudalism” which shape the landscape within which we live and work. Disengagement with psychiatry and the concurrent emphasis on employment, housing, education, etc., has moved the movement closer to the global system of international development initiatives. Here too, my interlocutors, grapple with Puar’s (2017) question—for disabled people in dire need of jobs to fulfil their basic needs, incorporation into a capitalist system, exploitative as it may be, is needed. These questions broaden the scope of what counts as ‘doing’ psychosocial disability with one participant explicitly linking state complicity with systems of economic exploitation and distress. They rhetorically ask “why are [farmer suicides]<sup>53</sup> not part of the psychosocial disability movement? Why is it a separate category?” (*Bhannu Priya*)

Third, while critical of oppressive systems as well as the solutions offered by the mainstream psychosocial disability movement, my interlocutors nevertheless engage with them. My interlocutors refuse the exclusionary version of disengagement with psychiatry, rather they continue to strategically engage it. While recognising the limits of legislation, they do not eschew it entirely but rather use it strategically. Their engagement with harmful institutions is not an uncritical acceptance or even attempts at small reformist action. It stems from an understanding that these systems cannot deliver justice and hence, is closer to the non-reformist reform or radical reform within abolitionist framework. Non-reformist reform can be one of many strategies employed by abolitionist organisers as a step towards the complete transformation of

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<sup>53</sup> This refers to the large numbers of farmers who complete suicide primarily due to crop failure and escalating debt. While this has been framed as a ‘health’ problem by public health actors, others have pointed to economic policies, climate change, and agricultural policy which favours the seed patenting industry. For more refer to Mills & Hilberg (2019) and Perspectives (2009).

carceral and capitalist systems (Kaba, 2021; Shehk, 2021). For some, it is distinguished from reformist reform by “its critique of the underlying conditions and the horizon that motivates the organizing efforts” (Marbre & Akbar, 2022, p. 1551). I argue that many of my interlocutors’ actions and activities can be understood through this lens. They consistently contextualise and localise the use of the tools such as the UNCRPD which are available to them. They aspire to not lose sight of the most marginalised and impacted people within the system, and consistently bring up caste, class, militarisation, and communalism as key axes of action. As the previous paragraph established, my interlocutors’ critique is intersectional and aimed at the root causes of injustice.

Finally, concerns about co-option and complicity are ever-present in the work my interlocutors do. In a departure from abolitionist organising around the Prison Industrial Complex, it is unclear what systems we have named as harmful and in need of abolition. In the absence of a clear shared abolitionist dream, the non-reformist reform way of ‘doing’ psychosocial disability is especially vulnerable to co-option. The danger of potentially radical work which “end up reproducing the system in another form” is a concern for many abolitionist thinkers as it is for my interlocutors (Kaba, 2021, p. 96). They consistently and continually weigh up the border between collusion and strategic use, between engaging with a system and being co-opted by it, and at the very least, aim to ‘do’ psychosocial disability in ways which are honest and transparent about its limitations and impacts.

In conclusion, an intersectional lens reveals how a single-issue view of understanding and ‘doing’ psychosocial disability can create exclusions and further inequalities. ‘Doing’ psychosocial disability from an intersectional lens requires activists to use institutions and discourses strategically and acknowledging the risks and limitations of doing so. Following from their understandings of psychosocial disability through disidentification with both psychiatry and disability, my interlocutors reject an ideologically pure or a singularly correct way of ‘doing’ psychosocial disability; rather they engage in an ongoing struggle to ‘do’ psychosocial disability in ways that are context-specific and with an intersectional lens. I argue in this chapter that the continued leadership of privileged people within the mainstream psychosocial disability movement obscures important issues and perpetuates marginalisation. In the next chapter I will examine the forces and structures which maintain the current hierarchical order of the movement.

*Interlude: on doing research in a burning world*

*It feels futile to do research in a burning world. I am not sure I have managed to convince myself, much less anyone else, that it is worthwhile to expend my energy (limited as it is) on research. In this endless parade of crises—some I can't even remember and others I think I will carry with me forever—two stand out.*

...

*The second wave of Covid in India started in April 2021 and lasted till July 2021. The UK, where I lived at the time, was talking about the upcoming "summer of freedom". And back home, a devastating wave of Covid spread unabated. It is hard to put in words the second-hand trauma of endless messages on our phones begging for hospital beds and information about where oxygen could be found. For weeks, I received the news of a family member, a friend, a distant relative or an acquaintance dying every single day. Social media was an endless scroll of pictures of mass cremations, doctors begging for medical supplies, harrowing tales of people dying in hospital parking lots. Our lives were characterised by terror for our loved ones and the overwhelming grief for dying and dead strangers.*

...

*Disability history is the history of genocide, of eugenics, of white supremacy, of colonialism. It is and has always been about who we allow to live, who we let die, and who we kill. What can I say about the genocide of Palestinians in Gaza which we have all seen unfold on our screens in the past year and a half? Working in and with disability rights was (and continues to be) a profoundly disconcerting experience at the moment. My social media feeds are filled with the horrors of what Israel (and the US, UK, and EU) are doing to Palestinians interspersed with the 'business as usual' tweets from so many disability activists and organisations, and worst of all, the loud silence of so many.*

...

*What does it mean to do research in a burning world?*

*I don't know.*

*The least I can do is leave evidence that when I was doing this research, the world was burning.*

## **VI. Coming together in neoliberal and fascist times: the contestations, exclusions, and flows of power within psychosocial disability activism**

[Psychosocial disability movement] wasn't something that I could count on, and it felt like everything that I had built my healing on was just taken away, whenever they wanted. And so then, of course, there's a lot of power struggles in the movement and who's voice is louder? Yeah, I, I'm very disillusioned. (*Anita*)

The previous chapters highlighted that psychosocial disability is understood as an identity, category, and a lens and it is 'done' within the spheres of psychiatry and human rights in a multitude of ways. Despite this multiplicity, the dominance of a singular narrative of psychosocial disability endures. I argued that this is in a large part because psychosocial disability discourses and action continue to centre an imagined and unmarked psychosocially disabled subject at the expense of those who are multiply marginalised. For me, this raises important questions about how the psychosocial disability movement is configured: How did the people I have identified as being on the margins of the movement come to be marginal in the movement? What ways of organising have come to be seen as *the* psychosocial disability movement and activism, and at whose expense? What systems uphold and benefit from the contours of mainstream psychosocial disability with all its ideological schisms and fractures? What can this tell us about the way power operates within the movement? By looking inward at the movement itself, this chapter unpacks how we understand activism and movements and the forces which shape them.

To answer the question of how psychosocial disability is 'done' within the psychosocial disability movement itself, i.e., how do the actors who occupy it organise themselves, this chapter unravels who these actors are, their relationships to each other, the structures they create and are constrained by, and how a context of rising authoritarianism influences what we can do and how we can do it. I argue that the neoliberal logics of NGOisation and the violence of Hindu nationalist fascism come together to create a reward and punishment system which excludes political readings of psychosocial disability and endangers those who seek to action them.

Psychosocial disability activism in India is shaped by the internalisation of neoliberal logics, particularly an ethos of professionalisation and individualisation. The process of NGOisation which favours hierarchical and professionalised organisations, an overreliance on distant donors and funders which encourage short-term tangible goals, and the individualisation of leadership which creates a closed group of well-networked elites lends itself to a depoliticised movement. As is well-documented in many contexts, these facets of psychosocial disability activism reward a

landscape characterised by formal well-funded organisations with short-term goals led by prominent visible leaders at the expense of intersectional action required to address multiple marginalisation (Jad, 2003). The possibilities of challenging/changing this system through the leadership of multiply marginalised people invested in an intersectional disability politics are foreclosed by the forces and tactics of fascism which punish actors and organisations deemed ‘too political’ through criminalisation and foreign funding laws. The status quo of a depoliticised mainstream psychosocial disability movement led by elites is upheld by confluence of neoliberalisation and fascism. Those at the margins of the mainstream, like my interlocutors, find themselves disappointed with the movement and throw into question the very meanings of the words ‘movement’ and ‘activism/activist’ within the context of psychosocial disability.

My analysis began with a rather simple question: do my interlocutors think there is a psychosocial disability *movement*? I asked my interview texts: in what ways and contexts do people use the word activist and/or activism. The first section of this chapter details the answer to these questions, and in doing so, tells us how ‘movement’ and ‘activism’ are understood more broadly. I argue that even within this small group of people, there is no unanimous or universal understanding of what constitutes activism and social movements. Rather these terms are given meaning by those who engage with them. Social movement, activism, and activist are used as signifiers to critique aspects of the psychosocial disability setting/sector, the particular ways of ‘doing’ psychosocial disability activism, and the characteristics of the people who are ‘doing’ it. In particular, they become ways to highlight the role of elites in de-linking radical identity politics from its material roots and the almost exclusive focus on individual visibility and prominence at the expense of long-term cross-movement engagement.

The second and third sections build on this to explicate how and why the psychosocial disability movement is structured the way it is, highlighting the role of NGOisation, the global donor and funding landscape, individualistic models of leadership, and the influence of fascism. In these sections, I find that the broader ecosystem within which psychosocial disability is embedded—fascism, neoliberalism, global philanthropy—undermines the liberatory promise of ‘psychosocial disability’. The confluence of these forces enables or rewards a particular type of single-issue depoliticised disability action while at the same time sidelining or hindering intersectional forms of ‘doing’ psychosocial disability.

Finally, in the last section, I examine the exclusions and violence within the movement and how these are perpetuated. I find that the exercise of power by those who hold it exclude certain forms of ‘doing’ psychosocial disability as well as the people who embody and push for

intersectional engagement. Drawing on concepts and literature related to social movements, I conclude that fascism and neoliberal logics work in concert to shape psychosocial disability activism and movements, further perpetuating the marginalisation of those who are the most harmed by them.

## **6.1 What is an activist and what is a movement?**

Despite the proliferation of the words ‘movement’, ‘activism’, and ‘activist’ as a suffix to psychosocial disability within literature and common parlance, when probed, my interlocutors expressed differing opinions on the meaning of these words. They spoke at length about whether there is a psychosocial disability movement in India, the reasoning behind their opinions, how they see and understand psychosocial disability activists, and whether they identify as a psychosocial disability activist themselves. In and of itself, this adds valuable contributions to our understanding of how psychosocial disability is ‘done’ in India. Beyond that, it enables a closer examination of how social movements and activism/activist are understood more broadly. Focussing on my interlocutors’ understanding of a movement as well as insights from their understandings of themselves and others in relation to an activist identity, I highlight the following themes—the lack of a collective identity; the adoption of a de-radicalised identity politics; an insistence on ideological rigidity; the difficulties in defining common goals; the lack of connections with the grassroots and other movements; and the neoliberalised modalities or tonalities which psychosocial disability activists adopt. I conclude that this analysis reveals contestations about the shape of the psychosocial disability setting and the people within it.

### **6.1.1 A movement—or something else? Delineating what makes a movement**

Is there a disability movement in India?... definitely, there is a disability movement in India. (*Ambika*)

There was no movement there. There still isn't. I don't think there's a movement...

Yeah, there is no disability movement. I cannot still claim a movement. I can say that there are people saying certain things, doing certain things, stuff is happening. (*Falak*)

‘Psychosocial disability movement’ or even just ‘disability movement’ is a phrase that people, including me, other authors, and my interlocutors, use to describe the collection of actors and organisations which constitute psychosocial disability action. Even *Falak* who, in the quote above, is definitive about the lack of a movement used the term to describe psychosocial disability elsewhere in their interview. ‘Movement’ in such cases is not used to signify or refer to an academic or activist definition but rather unthinkingly and as a shorthand to describe the

broader realm of psychosocial disability. A close reading of what my interlocutors highlighted when they were asked explicitly about the existence of a movement reveals critical insights about how psychosocial disability action and the broader concept of ‘movements’ are understood by my interlocutors. This section, and indeed this thesis, is not particularly concerned with establishing the existence of a psychosocial disability movement or the lack thereof. As such, I do not define ‘social movement’ at the outset. Rather I am interested in understanding ‘movement’ as a signifier that is used to refer to certain aspects of psychosocial disability. What is this thing that is happening? We know that something is definitely happening, so how do people understand it?

Most of my interlocutors, when pushed on the subject, were not comfortable calling the psychosocial disability a ‘movement’. Across the interviews, I identified four main themes, which my interlocutors use in defining a movement—one, a shared identity; two, clear and common goals; three, a grassroots swell; and four, historicity. To draw out and unpack these themes, I anchor my discussion within *Falak*’s clear and concise reasoning on why there *isn’t* a psychosocial disability movement:

I don't think there's a movement. I think there are people claiming identity spaces. There's no movement. There are people working with legislature. There is no movement. There are people who are engaging with educational institutions. If you ask me if there's a cohesive disability movement in the way that there's a queer movement, there is not... And part of that is because I think we are looking at disability with a certain ahistoricity.

Is an actual movement in the way queer movements have resisted happening? No. Is something like the women's movement happening? No. Are we collectively, and again, collective is never inclusive of everyone, but are we collectively moving towards something? Is it clear what we are trying to do?

And the combination of identity and organizing is what has sustained queer movements, no? And so, so where is that with disability? What is this? What is this thing, it has not sprung from the ground fully formed to suddenly be named? (*Falak*)

First, the role of identity in a social movement is brought up in two ways by *Falak* and others—a lack of a cohesive and collective psychosocial disability identity; and the configuration of identity politics within psychosocial disability.

Many of my interlocutors pointed out that there is no unifying collective psychosocial disability identity around which a movement could be formed. As Chapter IV highlighted, my participants



are attached to and find meaning in different terms and identities related to lived experience of mental distress/alternative experiences—user, survivor, psychosocial disability, lived experience, neurodivergent, crip—and use these identity markers in shifting and varied ways. What is a strength of psychosocial disability as a term, i.e., it can capture different aspects of being, is a shortcoming in the context of building a movement founded on a collective identity. For *Falak* and some other participants, a shared collective identity is a foundational pillar of a social movement. Collective identity in this context has the potential to cohere a movement, unify people, and build solidarity (Polletta & Jasper, 2001). However, while identity has been a key part of the conversation in psychosocial disability realms, there is no unifying collective identity that coheres people together.

The existence of, and negotiation with, multiple identities can be generative, but according to my interlocutors, mainstream psychosocial disability is often shaped by a depoliticised and shallow form of identity politics. This is what *Falak* is describing when they say that there isn't a movement, just "people claiming identity spaces". Some participants argue that this has "ended up creating all these silos" by being asked to foreground only one aspect of one's identity, undermining the fluid, circumstantial, and intersectional nature of our identities.

So, you are a part of the trans movement. And then if you show up as a trans person in a disability space everybody's looking at you asking, "Why are you here?" ... you're constantly having to answer questions of why you here, why you there? Or what is your, which is the kind of the most legitimate space you should be in? (*Sanya*)

Other participants point out that even when intersectionality is embraced or discussed, intersectionality of identity is elevated at the expense of intersectionality of issues. In this way identity becomes divorced from the material concerns which gave rise to those marginalised collective identities resulting in a hollowed out form of politics (Táíwò, 2022, p. 1). My interlocutors bemoan how a "particular person that embodies intersectionality" is put on a pedestal or idolised.

It becomes a lot more about the personality as opposed to the principles or values or ethics...It becomes more of a popularity contest as opposed to really looking at the issue on hand, which is more important, you know? (*Ambika*)

We reach a point where it is hard to decide on what a psychosocial disability identity means, whether everyone adopts a psychosocial disability identity, and finally even where we are able to build a politics around a collective identity, the way it is mobilised is a long way away from the

anti-capitalist and anti-imperialist origins of this type of politics (Combahee River Collective, 1977). Critics of contemporary identity-based social movements argue that the revolutionary potential of identity politics as imagined at its outset, has been diluted and co-opted by powerful and privileged ‘elites’ working within an increasingly neoliberalised context (Táíwò, 2022). My participants’ simultaneous assertions that a movement does not exist because there is no collective identity and at the same time that a movement does not exist because it is just people claiming identity politics seem contradictory. But in the context of Olúfẹ́mi O. Táíwò’s (2022) critique, I argue that in both cases, my participants are referring to the lack of a political movement which employs a common identity to mobilise those at the intersections of structural and material oppressions towards a common radical goal.

Second, my participants highlighted the importance of common goal within a movement. *Falak* asks “are we collectively moving towards something? Is it clear what we are trying to do?”. Much of the last chapter was also concerned with this—the varied entanglements and interactions people have with the structures we are trying to change, abolish, or leverage. Does the psychosocial disability ‘movement’/sector have a clear and common goal? Can we agree on what the problems are and what the solutions are?

My interlocutors speak of two different settings with different priorities: first, a setting built on or at least preoccupied with identity, and a second grassroots setting occupied by NGOs focussed on implementing social policy and getting disabled people their entitlements. There is no consensus amongst my participants which of these constitutes the psychosocial disability movement. Even within the same interview, *Falak* at one point describes the grassroots work as the movement in contrast to “an identity politics that doesn't really want to engage with the sort of movement-based institution politics”. At another point, they describe identity-based setting as the movement rather than what they describe as the “NGO social policy space”. They, and others, describe the two settings as being at odds with each other (as opposed to arms of the same movement).

And there's a lot of defensiveness and everybody's critiquing everybody else, and then they're getting into fights (*Falak*)

A third feature of the public, scholarly, and my interlocutors’ imagination of a social movement is a grassroots swell, i.e., a broad base of people coming together. Almost unanimous in their critique of psychosocial disability, my interlocutors agree that psychosocial disability as an identity and a mobilising concept, is restricted to “urban elite spaces” (*Bhanu Priya*). For *Raya*, a young labour organiser, the ubiquitous use of social media within psychosocial disability activism

without “people on the ground to work” is the “worst for mobilisation” and is a “killer of movements”. Almost all my interlocutors explicitly state that “movements have to take on a certain attraction at the grassroots level” (*Renu Addlakha*). Beyond the mere inclusion of the grassroots in a movement in what they call a “sort of top-down benevolent dictator version”, for *Falak* and others, a movement has to come *from* the grassroots.

There’s no *kranti* happening. *Kranti grassroots se hoti hai. Grassroot pe bechaare hain log yaar. People are bechaar* [there is no revolution happening. Revolution happens from the grassroots. In the grassroots, people are poor, people are poor]. (*Abhishek Anicca*)

Despite the term grassroots coming up several times, usually positioned in opposition to an English-speaking urban elite, there is little explanation of what or who is included in these grassroots. For some, the word grassroots is just a different way of saying rural or poor. For *Falak*, it is everything, urban or rural, that get “bypassed in the super structure”. This understanding of grassroots embeds it in the flows of power, knowledge, and capital which shape psychosocial disability activist networks.

The idea of grassroots for me...is basically anything outside of this dominant rhetoric and the dominant rhetoric being precisely that which exists in legislature policy, any kind of funds moving. (*Falak*)

Finally, and relatedly, some participants critique psychosocial disability as having a “certain ahistoricity” (*Falak*). They ask of psychosocial disability “What is this thing, it has not sprung from the ground fully formed to suddenly be named?” Movements, for some of my participants, emerge from and evolve through long-term sustained organising at all levels, including and especially the grassroots. *Renu Addlakha* reminds me that movements “evolve over time” and that in the context of psychosocial disability, “we are looking at a very small-time scale”. This indicates that while there isn’t a psychosocial disability movement at the current moment, it could emerge over time and psychosocial disability with all its contradictions and contestations is a movement in the making. However, the fascist context of contemporary India which punishes cross-movement and politicised activism hinder the creation of a psychosocial disability movement in the shape of my interlocutors’ imaginations. In the next section of this chapter, I will explore how and why the psychosocial disability setting in its current form came to be, focussing particularly on the interplay between neoliberalisation and fascism. But suffice to say here, for some of my interlocutors, it has not formed through/with social movements, organising, or the ‘grassroots’ and as such, its standing as a movement is questionable.

In conclusion, the psychosocial disability setting is often described as a movement but at the same time, and when examined, it does not fit any common understanding of a movement. My interlocutors understand a movement in relation to a collective identity, a common goal, emerging from or at least inclusive of a broad base of people at the grassroots through a long-term sustained engagement, and in the image of other movements. Most of my interlocutors, if not all, are part of queer movements, environmental movements, labour rights movements, women's movements, anti-fascist movements, and anti-casteism movements. All these other movements have a strong sense of at least one of the four facets of movements which my interlocutors deemed important. They have a collective identity that is mobilised, for instance, the anti-casteism movement. They have/had clear and common goals for instance, the queer movement organised itself against Section 377. They have emerged from, or at the very least have the support of, the grassroots, for instance, environmental movements are led by Adivasi and rural communities. And finally, they come through decades of sustained organising, for instance, the labour movement in India.

My interlocutors come to psychosocial disability with frames of reference rooted in these other movements and find it lacking. Much of social movement theory is developed similarly; understandings emerge from examinations of certain movements which are then applied to other contexts. Many of these theories are rooted in studies of global North movements and do not translate into global South movements easily (Fadaee, 2017). Several scholars are calling for and building Southern social movement theories, in the plural, which are responsive to the particular contexts within which movements operate (Fadaee, 2014). Despite this emerging body of literature, there is no public imagination or academic theory of social movement which fits the contours of psychosocial disability activism. Whether it is a movement or not and according to what criteria, for me, is a secondary question. In the words of *Laila*, "things are happening, but I don't know what it is that is happening". The rest of this chapter will analyse what is happening, the structures and power dynamics which influence the way it is happening, and the effect this has on the psychosocial disability movement and those within it.

### 6.1.2 Activism without “placard carrying activists” and action without activism<sup>54</sup>

[understanding activist and activism] is a question of how people understand these identities, and how they identify with it, and what it means to them. And what meaning they give to it, and what meaning it has for them in their work, in their struggles. (*Harsha*)

Contestations about the word ‘activist’ emerged very early on in my interviews—some potential participants were reluctant to be part of the project stating they were not activists; others wanted to be identified as researcher, actor, advocate, or writer; and some used the term easily and without hesitation. Learning from my early interviews, I paid more attention to how people described their work, following up with questions about their understanding of activists and activism.

Much like I described in the section above with the word ‘movement’, sometimes my interlocutors used the word ‘activist’ and ‘activism’ without a great deal of thought or interchangeably with advocacy, advocate, or organiser. In other words, it was used as a shorthand for someone working within psychosocial disability. For other interlocutors, there were distinct qualities which describe a psychosocial disability ‘activist’ or an ‘activist’ more generally. My interlocutors pointed to four overarching themes—one, ideology i.e., what one believes; two, repertoires of action, i.e., what one does; three, modalities and tonalities, i.e., how one does it; and finally, groundedness i.e., one’s relationship to the ‘grassroots’.

First, several interlocutors identified activists vis-à-vis their ideology or as *Laila* put it, someone who takes “strong, radical positions” that are “outside the main position that everybody was conforming to”. This aligns with the understanding of activists as people who demand “fundamental social change” or “the overthrow of a social order but seldom just ‘reform’” (Tarrow, 2011, p. 215). The latter part of the quote—seldom reform—is reflected in my interviews. Participants describe the positions activists take as stringent; extreme; absolute; fixed, i.e., it is not just what you believe in but equally how ‘much’ you believe in it. This leaves little room for the messiness of psychosocial disability where, as Chapter V explored, structures are violent and need to be dismantled but at the same time need to be accessed and made accessible. *Aman* spoke at length about the difficulties of sustaining this “conviction unflinchingly” positing that it can only be “sustained by anger and sustained by injustice”. Connecting this to the kinds of antagonistic positions that are central to activism, he went on to say:

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<sup>54</sup> Quote from interview with *Aman*.

When you're an activist, you have to *necessarily* adopt rage as your modus operandi, because you have to break things down before you can reconstruct. So, at a macro level, I'm all for that. I'm all for creative destruction. I'm all for being brutally honest about how fucked up things are. (*Aman*) (emphasis added)

Because I think as activists, we also take certain absolute and fixed positions. And that often becomes difficult to have messy dialogues. (*Madhu*)

Some participants such as *Madhu* in the quote above, use 'we', identifying themselves as one of the activists they are describing and critiquing. Others, like *Aman* who primarily identifies as a writer, uses 'you', when describing activists, setting themselves apart from activists.

Second, participants refer to specific and distinct forms of actions undertaken by activists. For *Harsh*, activism involves a "certain reliance on...a repertoire of work or strategy". Several participants give examples of this repertoire in relation to psychosocial disability: mobilisation of communities; protesting; writing letters to government officials; speaking at events; campaigning. The validity of using social media to raise awareness, form community, and share personal stories as a form of activism is contested within psychosocial disability action. *Sanya*, an older activist working at the intersection of gender and disability, describes this contestation as one between generations wherein some people see the increased use of social media by younger people to "articulate their issues" as a "trivialisation of the issue". Others critiqued it for lacking the radical edge of other forms of action. It is hard to untangle whether these contestations emerge from the use of digital repertoires in general or from the narrow actions which constitute digital 'activism' within psychosocial disability.

Several interlocutors describe their own changing identification as an activist in relation to the type of action they were undertaking at the time. *JJ*, now a scholar-activist, told me that when they were working on "going out into the community and making services accessible to people", they did not see themselves as an activist. *RP* also described her changing relationship with being an activist:

I have done a lot of activism. I have been an activist...when I was in the previous organisation where we were fighting for a lot of things and writing letters to the collector and doing a lot of protests and all of that. I don't do that now...I am more with the peer group and building them...So it may not be my voice asking for anything. It will be a group's voice. I'm still—I'm called an activist over here, but then I'm not doing that kind of activism. (*RP*)

Repertoires of action is a well-theorised concept referring to the strategies and tactics of activism and social movements (Tilly, 1995). Global South scholarship has particularly focussed on the localisation of the repertoires of action, emphasising that different power structures and histories of activism and movements give rise to actions that are context-specific (Bayat, 2017; Fadaee, 2014, 2017; Grech & Soldatic, 2016; Rai, 2013). For instance, the decades long use of *nukkad natak* (street theatre) by activists and organisers in India, including by some psychosocial disability organisations, emerged as a way to build political consciousness within the context of low mobility and low literacy under British rule in India (Seth, 2019).

In contemporary times in India, there are distinct differences between activist action in other movements and within the contemporary psychosocial disability movement. For instance, despite interlocutors citing protesting and mass mobilisation as key parts of the psychosocial disability activist repertoire, much of the action of the psychosocial disability ‘movement’ has been focussed on lobbying, legislative consultation and what *Madhu* bitinglly calls “intellectual masturbation and writing papers”. This is also a distinct disconnection with the kinds of disruptive action my participants have engaged in within the context of other movements—the months long farmers protest which occupied key roadways in the capital city <sup>55</sup>; the Narmada Bachao Andolan which used sit-ins and hunger strikes <sup>56</sup>; anti-CAA and NRC protests such as Shaheen Bagh, amongst others <sup>57</sup> (Chakrabarti, 2022; Chopra, 2021; Oza, 2022). This, possibly,

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<sup>55</sup> Following the public release of three farming bills, farmers (particularly from the states of Punjab, Haryana, and Uttar Pradesh) organised widespread demonstrations and protests. In 2020, 2021, and 2024, tens of thousands of farmers marched to Delhi, occupied and blocked key highways in and out of Delhi, called for a 24-hour strike resulting in 250 million workers going on strike, and disrupted railways. For more refer to Singh (2024) and Vasudeva (2024).

<sup>56</sup> The Narmada Bachao Andolan, a movement led by Adivasi communities, was a decades long struggle against the government’s plans to build multiple dams which would displace thousands of communities and cause ecological damage. In addition to legal battles, the movement utilised hunger strikes, sit-ins, and large protests. For more refer to Oza (2022).

<sup>57</sup> The Citizenship Amendment Act (CAA) is an Islamophobic piece of legislation which allows routes for citizenship for refugees/migrants from neighbouring countries except Muslims. The National Register of Citizens (NRC) requires all residents of India to produce extensive documentation proving that their ancestors were born in India, a task which is nearly impossible for the vast majority of people. When implemented together, the acts would exclude Muslims from having or acquiring ‘citizenship’. As part of the broader protests against the CAA and NRC in 2019-2020, Muslim women led a 100-day long sit-in on a crucial road in Delhi. Despite facing police brutality for the whole period, the Shaheen Bagh protest only ended due to the Covid-19 pandemic. For more refer to Khan (2023) and Ali (2024).

All three of these examples used disruptive and spectacular repertoires of activist action alongside practices of community building, art, and care work.

strengthens my interlocutors' reluctance to call the psychosocial disability setting a social movement.

A third characteristic associated with activism, according to my interlocutors, is the modality and tonality of action. For many, activism and activists are loud, visible, and persistent. Words like “fighting”; “fight a lot”; “being loud”; “shouting”; with varying connotations came up a great deal. “Fighting” is particularly interesting because it was used both positively as in fighting “against structures of oppression” or fighting for the community but also to describe an unnecessarily antagonistic way of being or as *Harsha* put it activists “lift[ing] their middle finger” against anyone they disagree with, including fellow activists no matter how immaterial the disagreement. In the latter case, ‘fighting’ is not just a strategy or modality reserved for challenging power structures but rather a way of being. For *Harsha*, whose work spans research, legal advocacy, and activism, the main distinction between activism and other forms of action is not necessarily the goals or the beliefs underlying them; but rather the “predominant modality that you would identify with”.

I suppose activism requires a certain kind of optic, or a certain strategy to put your voice out there. You know, it could be tonality, it could be loudness, it could be the aesthetics...So I think there is a certain aesthetics and optics to it, which probably kind of creates the difference between, say, activism, advocacy, and involving in research practice. Even though all three would be doing what each other does. (*Harsha*)

The centrality of visibility/loudness of activism was oft repeated. *Harsha* described a “certain kind of optic” and the “aesthetic” of activism as a strategy. Others, like *Laila*, have pointed out that psychosocial disability activists in particular are far more concerned with what they call “spectacle”. For them and others, visibility, loudness, spectacle, and the optics of activists, have become less strategy but rather a goal in and of itself, a “performance of righteousness” (*Aman*). The role of visibility as a key characteristic of the psychosocial disability ‘activist’ is particularly important in shaping its current landscape as visible activists from targeted communities (Dalit, Muslim, Kashmiri, etc.) face increasing criminalisation (Vijayan & Rechia, 2023). This, hence, reduces the possibilities of a psychosocially disabled activist from such a community from occupying a leadership position within psychosocial disability.

The image of the tireless, productive, consistent, and persistent activist unflagging in their convictions and action is a common one, including within my interviews (Bobel, 2007). *Gopika Bashi* describes the “normalisation” of a certain type of culture within human rights work where there is a mentality of and pressure to “give everything for the cause”. This idealised version of



an activist is hard for most people to relate to but for disabled persons, it is at complete odds with their lived experience (Piepzna-Samarasinha, 2018). The expectations of the tireless individual activist have been further cemented by and through the neoliberal drive towards professionalisation of activism (Jad, 2003).

Fourth and finally, being connected to the grassroots comes up again as a fundamental quality of a ‘good’ activist, as it did in the sub-section above. *Madhu* describes her work as activism which stems from “having your feet firmly on the ground in the realities”. While some interlocutors were reluctant to describe themselves as activists to distance themselves from the loud, visible, and ideologically rigid idea of a psychosocial disability activists, others, like *Aman* who is primarily a writer, were not comfortable calling themselves an activist because they have “never really been on the ground” (Bobel, 2007). For my participants, being connected to the grassroots is what an activist *should be* and is brought up often in contrast to the rather ugly picture of what mainstream psychosocial disability activists are today, i.e., primarily focussed on individual prominence and visibility. *Aman* sarcastically and vividly describes current activism as a:

Sort of civilisation, society, liberal circles, you know, sort of champagne sipping Lodhi garden type sort of liberal ecosystem, which I’ve never been part of, thankfully. You know, this sort of save the world saviour complex, which is very, very colonial by the way in nature, right? (*Aman*)

In conclusion, ‘activists’ and ‘activism’ are terms imbued with meanings that can be understood as either positive or negative depending on the person doing the activism, where they are located, and their intentions. In other words, they are not consistent labels. For some, it is an identity that describes their work, their ideologies, and their communities. For others, it is a label ascribed to them, one that they may or may not be “wedded to” (*Harsba*).

I don't know what the designation of activist means, but now everybody calls me that. So, I'm like *achha theek hain, chalta hain* [okay, fine, it will do]. (*Falak*)

The criteria against which my interlocutors measure psychosocial disability’s standing as a movement—shared identities, common goals, grassroots support, historic rootedness—tells me how they understand the setting, its contestations, and its limitations. Similarly, the values ascribed to being an activist—ideologically rigid, visible, loud, antagonistic, groundedness or lack thereof—are not inherent qualities of activism or activists. Rather they have come to be seen as features of activism and activists by my interlocutors because of the way the psychosocial disability setting is shaped. The preoccupation with what is ‘real’ i.e., the grassroots, the ground

realities; the contradictory telling of what an activist is; and the confusion over whether there is a movement or not highlights that many of my interlocutors feel a sense of disappointment with what's happening at the moment. The next section examines the structures that have given rise to this state of affairs.

## **6.2 The structures which shape psychosocial disability movement/activism: organisations, funders, and models of leadership**

I suppose these [activist/advocacy] different modalities have certain structures, and a certain set of institutions, and certain kinds of relationships, and certain kinds of modes of engagement which define the identity of that modality. (*Harsba*)

The preceding section highlights two key threads which characterise the psychosocial disability movement—one, a setting occupied by elites espousing a hollow form of identity politics with no grounding in grassroots movements or common goals; and two, the dominance of individual activists who are concerned with their own visibility and are unwilling to accommodate diverse ideologies. As *Harsba* points out, the modalities that activists use are embedded within structures, institutions, and relationships which dictate the repertoires of action that are available and advantageous to them. This section looks at these structures and institutions i.e., what some participants have termed “the activist ecosystem”. The psychosocial disability ecosystem is a collection of the NGOs, DPOs, and informal collectives of actors; their international partners and affiliations; and the funders and the funding structures that they rely on. The ecosystem exists within a broader capitalist and increasingly neoliberal context. I argue that the process of NGOisation, the global funding ecosystem, and models of leadership built on the neoliberal logics of professionalisation, competitiveness, short-term and tangible goals, and individualism rewards formal organisations led by charismatic leaders who have extensive links to international funders and punishes those who do not fit this model. In this section, I look at these three structures and processes—NGOisation, funding, and leadership—and how they operate within psychosocial disability activism in India.

### **6.2.1 Trajectories of NGOisation: organisations, not organising**

As Chapter IV establishes, ‘psychosocial disability’ as an identity and a framework emerges from and is linked to ideas of community and collectivity. *Anita* stated explicitly that they “entered this space for my own healing”. Other interlocutors talk about their desire to make meaning, connections, and foster a sense of belonging through involvement with the psychosocial disability movement. However, much of the psychosocial disability ecosystem, is not primarily

concerned with personal meaning-making and healing but takes the form of structured organisations. I use the concept of NGOisation, which Aziz Choudry and Dip Kapoor (2013) define as “the institutionalization, professionalization, depoliticization and demobilization of movements for social and environmental change” (p. 1), to examine three main facets of the psychosocial disability sector. First, the professionalisation of activism and the internalisation of capitalist and neoliberal logics; second, the imposition of a template-based model of organising; and third, the particularities of the trajectory of NGOisation within psychosocial disability movements.

First, professionalisation of activism is a critical facet of NGOisation. For my interlocutors, whose engagement with psychosocial disability is linked to healing and community, professionalisation, and more broadly NGOisation, resulted in a situation which “significantly alter[ed] local groups and alienate[ed] members” (Meyers, 2016, p. 1).

I feel like from my experience was that by the time I left it, it was just work, it wasn't a community anymore. It wasn't something that I could count on, and it felt like everything that I had built my healing on was just taken away. (*Anita*)

Professionalisation, especially in the neoliberal context has very specific impacts on people with psychosocial disabilities. As *Raya* put it, the “structural setup”, primarily consisting of large, professionalised NGOs even when led by persons with psychosocial disabilities, automatically reduces “the space for madness”. Capitalist work cultures characterised by a hyperfocus on efficiency, productivity, and competition, are incompatible with the accommodations mad and disabled people require. Furthermore, when such cultures are adopted by the very settings we hope would challenge them, the negative impact is profound.

You know it was not about support anymore; it was about work. It was about like a paying job, you know. And I feel like these spaces, they are extremely cutthroat. (*Anita*)

Many of us were asked to work even when we had COVID during this second wave, smack bang in the middle of the second wave... We were claiming to not be ableist but also being very ableist in practice. Demanding people's time, demanding work to be done according to their schedules and not checking in with us. (*Anita*)

*Raya*, part of a small collective, described their attempts to “unlearn this idea of hyper productivity” and for their collective to “adopt a whole different pace”, creating internal mechanisms which would both provide room for crip ways of working and satisfy the demands of their funders. For them, this is inextricably linked to accessibility, and what they call the

“deeper work on accessibility” i.e., thinking beyond tangible things such as ramps and sign language interpreters. Beyond the personal impacts on people such as alienation, exacerbation of disabilities, and disappointment, *Raya* emphasises that radical systemic change, consciousness raising, and sustained intersectional movement building, what they call “political conversations”, need “long-term sustained conversations”. For them, this is simply not compatible with “nine-to-five” ways of working which leave little time or energy to engage in such conversations.

This whole NGOisation, what has it meant for movements? What has funding done or largely sort of this mainstream developed agenda, co-option of some of our movement politics into those so-called mainstream agendas. Like even if you look at these sustainable development goals and rubbish ‘leave no one behind’. It’s just like a lovely tagline because what does it even meaningfully mean to do when leave no one behind? And the damage and the harm that’s done. (*Sanya*)

The formation of organisations which internalise the logics of neoliberalism and ensuing professionalisation does not simply take the place of political mobilisation and organising, it actively hinders it. NGOisation in this context harms both the folks we claim to work for *and* ourselves.

Second, and in the specific context of psychosocial disability, organisations follow a template-based model imposed by, or at the very least encouraged by, international instruments and institutions such as the UN and the UNCRPD.

NGOisation usually refers to how social movements slowly change through the formation of large professionalised NGOs and leave behind the radical politics that they were founded on (Batliwala, 2002). However, Stephen Meyers (2016) argues that the end result of NGOisation is inherently built into the UNCRPD through its mandate that “disabled persons organisations (DPOs) be involved in the interpretation, implementation, and monitoring” of disability rights (p. 2). In other words, the UNCRPD does not facilitate social movements, rather it creates a web of international and national organisations, platforms, donors, and mechanisms that follow its ratification. This is echoed by *Renu Addlakha* who explains that the UNCRPD and the broader web of global disability organisations has imposed a “template-based” and “top-down way of construction of a movement” wherein every country has “a national federation, then...all these members”. For psychosocial disability which first appeared on the scene with or because of the UNCRPD, the result is a setting which was grafted into a context rather than emerging from it. As such, it looks remarkably similar across global South countries.

You know how the disability rights funding has been so, like linear. They were, “Oh yes, now we have UNCRPD. Yes, now we have Disability Rights Fund. Yes, we will fund national level [laughs] Federation, who will control every damn thing, including your every piece of thought. I mean, it’s been so bizarre and so problematic. (*Renu Addlakha*)

The activism ecosystem functions mostly in the western neoliberal space, which has a vocabulary for everything, which has etiquettes, which has tokenism, which has inspirational stuff going on.... It is a well programmed machine. [sighs] (*Abhishek Anicca*)

We can see the results of this template—a national federation with member organisations—within psychosocial disability. Since power is vested within the national federation, a key goal of early psychosocial disability organisations was to be included within the existing federation system, thus legitimising their position as a disability organisation. However, the homogeneity of the imposed model of organisations reduces the possibilities for localised and diverse organisations.

Beyond the structure imposed by the UNCRPD and its related global North-based organisations, within India the larger or more powerful NGOs are often urban-based and centralised, and reach out to ‘peripheral’ areas, propagating a similar top-down and template-based model. Where different regions have radically different socio-political contexts and concerns, NGOs born out of and located in urban areas in Mainland India are grafted to contexts where they are not useful. *Anita*, an early interviewee from the highly militarised region of Northeast India, referred to this while drawing parallels to the coloniality of wholesale importation of models, ideas, and structures:

We talk about this thing in the disability movement about how global mental health imports models into the global South, but aren't we doing the same with Mainland India and the Northeast, because we're not acknowledging the realities of life in the Northeast, we're not acknowledging the intersectionality of identities there, for example...so many NGOs from Mainland India in mental health or disability go there and they do these things. It's the colonialism in a way. You know they're still taking, importing ideas and they're still refusing to acknowledge the realities of people who might not be their own. (*Anita*)

Third, in contrast to the better studied course of NGOisation wherein social movements become depoliticised through the formation of NGOs, other trajectories of NGOisation are relevant to psychosocial disability, wherein:

some Third World NGOs – often funded by Northern NGOs, private foundations and government development assistance programs – have been vehicles for relatively privileged intellectuals to research, or to conduct professionalized lobbying of, governments or international institutions, but have later reached out to social movements as their legitimacy. (Choudry & Kapoor, 2013, p. 8)

Since a large portion of the contemporary psychosocial disability movement has been internationally grafted, there is a lack of strong connections with other movements. *Renu Addlakha* contrasts the “grafted” movement in the global South with the North where she says the movement “evolved gradually through a lot of struggle and organically”. This is not a unanimous opinion in the literature or within my interlocutors. Davar (2013) has highlighted the roots of the psychosocial disability movement within the women’s movements in the 1980s and 1990s as have some participants. At the same time, the dynamics of the UNCRPD imposed structures make it clear that many of the organisations which populate the psychosocial disability setting did not emerge from movements to be formalised and professionalised at a later time. Rather, they started as structured and professionalised formal organisations and “later reached out to social movements”.

Psychosocial disability settings in India are populated by a loose collection of the type of organisations described above. Scholars and activists alike have warned against conflating NGOs with social movements (INCITE!, 2017; Jad, 2003). Islah Jad (2003), within the context of Arab women’s movements, argues that NGOs are limited in their ability to mobilise a movement due to “the fragmentation of issues they deal with, the temporality of these issues and their resources, and with their weak social networks” (p. 38). This resonates with the concerns raised in the preceding section, i.e., the psychosocial disability setting is divided over identity and common goals, separate from historical and contemporary grassroots movements, and hence, lacks the constitutional elements of a social movement. The psychosocial disability setting, which was created in large part by the external imposition of a network of professionalised organisations, is particularly prone to the depoliticising effects of NGOisation.

## **6.2.2 “The revolution will not be funded”: donors and their demands <sup>58</sup>**

A key aspect of psychosocial disability in India is the donor organisations and broader funding ecosystem, and all interlocutors spoke about the difficulties of navigating it. They linked the

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<sup>58</sup> The title of this sub-section is a reference to the title of the book “The Revolution Will Not Be Funded” by INCITE (2017).

professionalisation and formalisation of the psychosocial disability sector to the demands of funders and the logics which underlie the broader donor and philanthropic ecosystem.

Before diving into the intricacies of the disability funding landscape, I must acknowledge a central conundrum that it presents. While the idea of a “paid activist” is distasteful to many and produces a myriad of issues, outside of disabled-led organisations, disabled people are often exploited by NGOs and other sectors. Their life stories are used without compensation for the benefit of organisations, they are often paid less than their able-bodied/minded peers, or sometimes not paid at all. Further, psychosocial disability-led organisations in whatever form they exist require money to do the work they want to do. The critiques offered by me and by my participants are aimed at the way the broader funding ecosystem operates rather than the idea of being compensated for your work. They highlight the prominence of foreign funding within psychosocial disability; the elevation of some issues and people; the focus on project-based and tangible deliverables demanded by donors and its negative implications on intersectional engagement; and the deep impact of over-reliance on funders and donors on the sector and the people trying to navigate it.

First, and as mentioned in the sub-section above, much of the psychosocial disability ecosystem is internationally grafted, and that includes funding. *SL*, now a freelance artist, unequivocally states that most funding for psychosocial disability organisations is “private, most likely from white organisations abroad”. *RP*, a senior activist in the movement who runs her own organisation and has a deep insight into the entire ecosystem, explicitly links the process of NGOisation to “foreign money” which “has killed the spirit of movements”. Further, it de-localises and de-contextualises the priorities of the movement.

And [foreign funding] in itself would create a hierarchy where we want a western approach to certain things because it's easier to look at things when it's categorised into a similar box than when it's a completely different experience and challenge... it's easier for the funders to view it through that lens than to understand the culture you work in.  
(*SL*)

Strategic use of certain types of language, discourses, and imagery (even if problematic) to garner favour with or leverage international centres of power is a well-known tactic of movements and organisations (Fadaee, 2014; Karter, 2021). However, problems arise when these ill-fitting, albeit sometimes useful, discourses get internalised and begin to drive the agenda. Elites within the global South (me included) hold positions of power within the psychosocial disability sector. Their/our class, caste, and urban English-speaking positions influence ideas, and with the help

of global networks of power and capital, actions (Development Initiatives, 2024). In this way and through proximity to global centres of power, a section of elites, a North within the South, consolidate their power.

Because those people are coming from major metropolitan cities which are of course heavily influenced by an outside perspective. Often people want to be like they're American or something, often upper-caste people want to be like that, and there's part of race and caste that bind into it. So, I think their stories just don't look like they're culturally relevant sometimes. *(SL)*

Second, many interlocutors pointed out that funding/donor/philanthropy comes with a specific type of ask—tangible and documentable wins.

And I think because the larger environment where the sort of the rights-based work happens and the advocacy happens...everything is all about getting there quickly, outcomes, victories, wins. *(Sanya)*

Systemic and radical change cannot work on the timelines demanded by the funding ecosystem, neither can it be quantified in the same way. Furthermore, it requires intersectional mobilisations and the political project of “alliance building”, which for *RP* “cannot ever be a funded project”.

There's a lot of work to be done if we really want to promote intersectionalities, and I don't think a lot of it is very thought through. And I think that it's cyclical because donors who are investing in intersectionalities are not really keen on going into that much depth. So, it's kind of like, piecemeal-y about it. *(Naina)*

Third, dependency on this ecosystem means that “you have to constantly be raising funds” *(Laila)*. Successfully raising funds is dependent on aligning one's organisational goals with the foundation's priorities (Oyakawa, 2017). In the international funding ecosystem, which is deeply embedded in global capitalism, where “being critical doesn't help you raise funds” *(anonymised)*, any radical edge of activist ideas and actions gets blunted. In other words, “the NGO begins to focus on specific results and funds, rather than on ethics or shared values...In order to survive and achieve positive political influence and access to funds, NGOs become ‘colonised by governmental ways of doing business’”(Gonzalez, 2021, para. 5). Instead of the funding ecosystem *supporting* the work of a movement, organisation, or a sector; it *drives* it, shaping what can and cannot be done and the ways in which it can be done.

And for NGOs, our main customer is the funder, not the people we are working for, and that's what leads to dilution of movements. *(Raya)*



This is a key link in the process of NGOisation which creates and rewards organisations who move to a project-based way of working instead of the slower and less linear process of political mobilisation. *Bhanu Priya*, a psychosocial disability activist, talked at length about their experience of starting a collective which works on political education and mobilisation on issues of disability and caste in both the anti-caste and the disability movement.

The work of our collective, actually any collective or any group, any organization, they start with some goals and vision but then funding comes in between and then projects run. [laughs]...and I think what is needed is to constantly remind us that this is our vision and to not get stuck with projects. (*Bhanu Priya*)

They went on to say that their work “is very much dependent on the funding we get and on the kind of donors we have” referring to the ethos of a donor agency. *Bhanu Priya* was unequivocal that having a progressive and non-interfering donor enabled them “to do the kind of work we’ve been able to do”. Even within this more permissive donor relationship, they still had to spend time and energy bringing out a publication as a “project deliverable”. Referring to the issues created by the funding ecosystem, *Sanya* a senior feminist activist reflected on the work they did on “funder education” and the need to “influence the entire ecosystem”.

We had to do a lot of work in kind of impressing upon them [institutional funders] that the way that they were thinking about the so-called funding outcomes, etc, were just simply not the way this work could happen. And we were lucky that way. In the end I think a lot of the funders realised it, recognised it, and, you know, we ended up with a lot of like really flexible core funding that allowed us to do the work that was not so projectized with deliverables and outcomes. So, to that extent, we were very lucky. (*Sanya*)

It is important to note, that despite being at the head of a relatively influential feminist organisation in India, one that itself funds other organisations, *Sanya* still emphasises the fact that they were able to do any of this type of work because they were “lucky” to have flexible funders. For both *Bhanu Priya* who runs a small collective, and *Sanya* who worked within a larger more influential organisation, their ability to engage in the work they believe in happens at the behest of the donor organisation. In other words, organisations which rely on donor funds become accountable not to the movement, but to the funders.

The funding ecosystem works hand in hand with the leadership of middle-class urban Savarna people in the psychosocial disability movement with grave consequences: one, it affects the

priorities of the sector; two, it depoliticises it and changes how it works; and three, it creates a closed system of power and capital. There is no straightforward solution to navigating this system. One well-established activist is selective about the kinds of funding they will take:

I would not take funding from International Disability Alliance because they want you to toe a particular line, which I'm not going to. I like the freedom being given. And International Disability Alliance will have one kind of people, and I don't want any restrictions. (RP)

But younger activists, especially those who are not in decision-making capacities, find themselves unable to do that. *SL* provides a chilling example of the insidious impact of the power that funders hold. They were at a conference listening to a session on “mobile-based solutions for mental health challenges in India”. They raised questions about the accessibility of apps and their inability to change “deep oppressive systems” which create distress, going on to describe the consequences:

I remember being called out by my mentor at that time...Because in the back of my head I didn't realise that one of the major fundings they are getting is from a tech company to make an app. And which they just got that very day of the conference...I also noticed later on that she ignored me throughout the day and kind of made sure that I am ignored. It was a way to show that you've done something wrong. (SL)

In conclusion, the neoliberal logics of the large funding organisations which support psychosocial disability NGOs create a setting based on competition rather than collaboration, time bound and single-issue projects rather than intersectional and systemic change, a small group of elites rather than mass mobilisations, and action led by and in service of donor priorities.

### **6.2.3 “Larger than life”: a critique of individualised stardom as leadership**<sup>59</sup>

There is no doubt we need leaders, but there is a point where the leader takes over and the hierarchy happens. (RP)

In the first section of this chapter, I highlighted that visibility is a key component of psychosocial disability activists and leaders. In and of itself, a certain individual or a group of them holding leadership positions is not deleterious. However, as the quote above explains, vesting power,

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<sup>59</sup> Quote from interview with RP.

visibility, and influence in one person can create and perpetuate hierarchies. A model of leadership influenced by NGOisation and rewarded by funders has become prominent within psychosocial disability in India. It is characterised by individualised leadership which lends itself to a heightened focus on visibility and performance as well as the consolidation of power within a small group of elites. It is these aspects of individual leadership which are critiqued by my participants.

What I notice in the disability sector here locally, individual activists become very famous, and they become larger than life. They're all friends, which is great. And so, they become so great that they are able to mingle with the top-class, top-grade politicians. The powerful people of the state, which is also great. But if that is not going to help the people, then why would anyone be an activist in the first place? Because...nothing moves on the ground. But the activists are very famous. I mean, for what? (*RP*)

*RP* highlights three factors which embed a harmful model of leadership within the psychosocial disability movement: one, fame and visibility; two, relationships with powerful actors; three, a closed network of “friends”. I will take each of these in turn.

First, as the first section of this chapter emphasised, “advocacy has become synonymous with visibility” and “steeped in hierarchical thinking” (*Aman*) i.e., one’s work is only considered as important activism and advocacy if it is visible. Consequently, a significant part of a person’s work is geared towards gaining and holding on to visibility. *Aman*, an outsider to the mainstream psychosocial disability movement, contrasts this with what ‘advocacy’ is supposed to be:

[Advocacy is supposed be] an assembly line of ideas and people where you get to be, you know, at the centre of the conveyor belt for a period of time. But then the conveyor belt cannot stop, and you can’t be the only suitcase on it, right? And that has not happened. (*Aman*)

Second, the NGO funding ecosystem is largely based on informal relationships, often forged at international gatherings of powerful disability actors or what *SL* calls networking in the quote below. For an organisation to survive, they need to send the same person to all such events to sustain donor relationships. Consequently, this consolidates the soft power these actors have. The system creates “actors with parallel powers based in their recognition at the international level, and easy access to important national and international figures” (Jad, 2003, p. 45). Here, the informal flows of power in the form of social and cultural capital are directly linked to flows of actual capital.

Just to take the example of why do some organisations only send a certain spokesperson? Because there's an idea that maybe they'll be able to charm and speak the best and they have certain qualities that people think are ideal for this western outlook of what it means to network and connect...I think it's done with the purpose—and often the purpose of many many conferences to me is networking and focusing on funding. (SL)

People are chosen who you know. And it's only people who prescribe to a certain agenda and a certain framework that are that are kind of also given a platform. (Anita)

Finally, it is important to note who gets elevated to these positions of power within the psychosocial disability movement—it is usually those who are normative in all other senses. In India, it is Savarna urban English-speaking people. Even when there is a push towards intersectionality, it is configured around an almost unimpeachable person at the top of the movement. Further, the reliance on funding systems, which do not reward deep intersectional engagement, creating an environment which focuses on a person, and not the issue. What *Ambika* describes below is in effect how identity politics in its radical beginnings gets captured by some elite persons:

I just feel like a lot of these things have become in a way where you put a particular identity on a pedestal. You know, you start preaching to this particular identity, to—'this particular body' is what I would like to call it, you know? This particular person that embodies intersectionalities, you know?...And then you start idolizing the person and it becomes a lot more about the personality as opposed to the principles or values or ethics...And I think that is where I see personally the failures of intersection that you start idolizing, and the minute you stop idolizing there's somebody else. It becomes more of a popularity contest as opposed to really looking at the issue on hand, which is more important, you know? (Ambika)

In conclusion, hierarchical professionalised NGOs instead of movements; the funding ecosystem, its neoliberal demands and opaque functioning; and the lack of efforts or incentives to redistribute access to platforms, power, and resources create a closed system of elites in the movement. This is a frustration shared by many of participants, colleagues, friends, and me.

I feel that's the elitism making sure it's like a certain group and no one else enters the vault, sort of like thing. (SL)

The confluence of NGOisation and the funding ecosystem creates a situation where leadership is disconnected from what leaders are supposed to be leading, and they become accountable to

their structured organisations and funders rather than the movement. The resulting ecosystem internalises the neoliberal logics of professionalised NGOs and donors and therefore demands and rewards a certain type of activism and activist—visible, leading a formal organisation, and embedded within the global funding system—at the expense of those who do not fit this mould.

### **6.3 Organising in a fascist era: risks, repercussions, and strategies**

And of course, we are dealing also with a world that's increasingly like intolerant of movement space. I mean, look at what's going on in India, right? Like we're literally—like, even going out on the streets is now dangerous. Forget about organising coming together, you know. There's just so much scrutiny of the work that one does here now, depending on what kind of work you do. (*Sanya*)

The rise of Hindu nationalism, authoritarianism, and fascism under the Modi-led BJP government has had severe implications for all forms of activism and movements (CIVICUS, 2025). This is something that came up in most of my interviews, particularly from those who are from or work alongside communities most affected by the violence of the fascist state. This section examines the influence of Hindu nationalist fascism on the psychosocial disability movement. First, it examines the tools that the state uses to repress activism and their impact when combined with the neoliberal pressures outlined in the preceding section. Second, I focus on how the combination of state pressure and the circulation of fascist beliefs within the disability movement contributes to the depoliticisation of disability activism. Finally, I highlight the ways in which activists leverage depoliticisation strategically and open new ways of understanding disability in the face of explicit and spectacular state violence.

First, the Indian government uses formal tools—organisational audits, restrictions on foreign funding, and criminalisation and imprisonment of activists—to intimidate and punish activists and others in activist-adjacent settings (Human Rights Watch, 2024; Vijayan & Rechia, 2023). Within the specific context of psychosocial disability, these tools work hand in hand with the demands of a corporatised movement to exclude and silence voices demanding a more radical political idea of disability.

Formalisation of an organisation as a registered and legal entity creates a particular set of vulnerabilities which then dictate what an organisation will or will not do. Organisations which engage in or are connected with others who are working on issues which challenge the Hindu nationalist or fascist underpinning of the Indian government face a host of consequences—frozen bank accounts, repeated and punitive financial audits, revocation of registration (Human

Rights Watch, 2024; Vijayan & Rechia, 2023). *Laila* relates the position of a mainstream psychosocial disability NGO during the 2019 CAA/NRC protests:

So, when CAA and NRC discussions were taking place, they had a discussion...So we did do something as part of the organisation [but]...the organisation is not going to enter the protest as an organisation because it's a legal entity and if they do get caught then they would be legally liable. The FCRA discussions were happening at that time as well. The organisation was about to place their registration for approval. The government can cut your funds and so I think there are real threats. (*Laila*)

An additional key vulnerability of organisations which came up repeatedly was foreign funding. The Foreign Contribution (Regulation) Act 2010 (FCRA) under the current government has been amended and utilised to scrutinize organisations which receive international funding. The devastating impact of FCRA on activism in India is well-established; organisations have been forced to shut down and funders have withdrawn when it comes to explicitly political work like anti-fascism, anti-militarisation, and environmental justice (Human Rights Watch, 2024; Robinson, 2024). For psychosocial disability movements which are completely enmeshed with, and in some ways created by, international funders, the FCRA has had a significant impact. A constant cycle of incoming international funding is required by the neoliberalisation of the movement and is punished by fascism. The process of becoming a FCRA-approved organisation is lengthy and expensive, opens an organisation to financial scrutiny, and demands that their activities must not be against “national interests”, a vague and loosely defined term (Robinson, 2024). To navigate this, psychosocial disability actors must exclude/shy away from topics deemed ‘too political’ i.e., Islamophobia, militarisation in Kashmir and Northeast, caste violence, religious persecution, anti-fascist and more generally justice-based work. They must then embrace a hollowed-out version of disability politics; one considered benign enough by the government to allow.

And the biggest problem has also been because of the FCRA. Because if we want to talk to a politician, if we want to put something in the manifesto, and it cannot be done with foreign money. So, what kind of conversation, who's happening, and where also depends on what kind of money you are getting and what kind of agenda you have set, or others are setting. (*Madhu*)

Furthermore, the Modi government has resorted to using terrorism legislation as well as other criminal charges to target and imprison human rights defenders (Vijayan & Rechia, 2023). Within activist contexts, there is a very real fear and threat of imprisonment. This has a chilling effect;

activists/organisational leaders are reluctant to talk about ‘political’ issues. Visibility, which the previous section highlighted is an important part of the psychosocial disability landscape, is hence punished by the fascist government. One must work under the radar of the government i.e., not be the visible to the government but as a consequence, not visible to the rest of the disability movement. Those most invested in ‘political’ issues, are unable to find the room to address them safely in the disability movement because it is structured around visibility; and those who are visible do not wish to risk the ire of the government and hence avoid ‘political’ issues.

We are also resisting website because some of the fellows said that you know, we do not want our work to be published. They are like we do want to write; we want it to be stored, but I think there is a fear in this current moment from Dalit queers, Bahujan queers to write something about...Like right now we are highly bothered about hate speeches and killings. And it is not that somebody else is getting killed, you know, these are friends, those who are living in our communities. (*Roop*)

So, when I bring [Kashmir] up in some space—early on when I used to bring it up in spaces...I think everybody agrees on principle. It’s the repercussions of what it means when you do it that maybe people are not necessarily agreeing on. Is this a cost we want to have, right? (*Neha*)

A second facet of the rise of Hindu nationalism and its ensuing effect on psychosocial disability is the presence of those who espouse the ideology within the movement. This, along with the real and grounded fears of anti-fascist organisers, has contributed to a depoliticised and benign form of disability politics. Several participants, some on the record and some off, and my own experiences within the movement show that “there is a lot of right-wing identification within the disability community” (*Neha*).

Due to the purposive choices I made about who to interview and my transparency about my own politics, none of them professed any affinity to Hindu nationalism explicitly. But even so, there were hints of apologism or minimisation of the impact of the rise of Hindu nationalism on the communities it targets.

People not acquainted with the disability movement in India are sometimes shocked when I talk about parts of the disability movement being aligned with or supportive of the Modi government and its Hindu nationalist agenda, largely because the words activists and social movements are usually used in relation to progressive politics. However, the psychosocial disability movement is

largely grafted on to India, i.e., it either did not grow from or lost its early links to other social movements and, hence, did not inherit or nurture India's established traditions of radical and intersectional politics in social movements. Further, some interlocutors opined that part of this right-wing identification in disability settings comes from "experiences of marginalisation" and historic exclusion from politics as well as "because of how little the Left has done for disability" (*Neha; Sanya*). *Sanya* goes on to say that because of the exclusion of disabled people from the political realm, as soon as:

space starts opening up and you are able to feel like you have some power, have some voice, some representation, how quickly that is seized upon and in a way co-opted. Like where it's very much aligned to the government's politics. (*Sanya*)

A depoliticised and hollow disability politics which focusses on disability legislative reform and is isolated from progressive movements poses no danger to the Indian government. This incentivises the perpetuation of a depoliticised disability movement.

Third, despite the overwhelming violence of the Indian government, some psychosocial disability activists are continually adapting and trying to find ways to leverage or challenge the depoliticisation of disability. Authoritarian states in the global South tend to see 'disability activism' as a benign form of activism in comparison to movements focussed on political prisoners, land rights, or anti-militarisation (Mullins, 2021). The public and the government's imagination of disabled people as objects of charity can be leveraged to keep oneself off the list of enemies of the state. One participant describes how they have used this to their advantage when crossing India's international borders:

I have been detained at immigration twice while traveling out of the country, asking me where do I work? Why do I have this travel history, etc. And I have to say, "Look, I work for disability. It's not political issue." You know, like, "Oh, poor disabled people. Let me go" [chuckles]. (*anonymised*)

Additionally, some activists employ strategic depoliticisation in their public-facing work, while at the same time finding and creating openings for more political discussion (Mullins, 2021). For instance, *Ambika* recalls when working on "comprehensive sex education which was banned in India", they started their trainings on "menstruation", a health issue rather than "consent and pleasure" as a way to sneak in the topics they wanted to address. Another interlocutor also referred to strategic diluting or deliberate ambiguity as a way to evade state violence and police intervention:



I'll just give you an example from yesterday. We were doing a small candlelight march for people who've died in wars, in genocidal wars like Gaza, like what's happening in Syria, like what's happening in Yemen... So we sort of, like, wrote a very ambiguous pamphlet, because we couldn't have written very politically considering that you also have to be very careful... So we need to be a bit safely, so the pamphlet was very simple. It was like, we are doing a candlelight memorial for people who've died in wars in the past ten years, but we've also explained what is the role of capitalism within that *parcha* [pamphlet].

(*anonymised*)

Finally, the fear and distress of communities in the face of explicit fascist violence as well as the specific cases such as the imprisonment and death of Professor G.N. Saibaba, a physically disabled activist, has enabled some people to make the links between state violence and disability (Saibaba, 2022; Vijayan & Rechia, 2023). *Naina* notes that while the movement as a whole does not want to engage “conversations around caste and disability, queerness and disability” as well as Kashmir, these conversations are “definitely inching forward” albeit in pockets.

How much disability was caused by pellet injuries? How much living in an occupied state causes PTSD, and so therefore psychosocial disabilities? What does it do to maternal health, therefore, what does it do to children's health? Right? I mean, we have these conversations, but it is an anomaly. (*Naina*)

Within the current contours of fascism in India, violence against people from marginalised communities comes through two main routes—through official legal routes and state violence and from within communities in the form of vigilante violence, violent rhetoric, economic boycotts tolerated/encouraged by the state. The increasing focus, albeit in small pockets, on the intersection of fascist violence and the creation of disability has the potential for new ways of understanding disability. For instance, understanding disablement on a community level when “[Muslim] communities are living under a more heightened state of distress” and in a constant state of collective terror and fear (*Harsha*).

In conclusion, the Hindutva fascist project in India has contributed to the depoliticisation of the disability movement and punishes those who challenge it, particularly those from targeted communities. The demands of the neoliberal underpinning of the psychosocial disability setting—visibility, formalisation/legalisation of organisations, and access to international funding—are in turn punished by the fascist state. Although, some psychosocial disability activists, including my interlocutors, are using strategic tactics to undermine it, this requires a

continued commitment to the “strategic” part of the process, but as the next section will elucidate, this is often not the case.

#### **6.4 Leveraging power: the perpetuation of violent exclusion**

I kept quiet because I was a younger person, just new to the field. And I remember saying this to a few colleagues that *paani main uttar kar magarmarch se nahin panga lete hain* [you don’t enter the water and pick a fight with the crocodile]. (*Chandra*)

Having outlined the shape of the psychosocial disability movement, the structures within the broader ecosystem that uphold it, and the political context within which it is embedded, I now turn to the ways in which power is exercised by those in positions of influence. As I argued in previous sections, those in positions of power within the psychosocial disability movement exert a great deal of influence in defining psychosocial disability, how it should be done, and as importantly, what cannot be considered to be part of the movement. Additionally, power and influence are usually vested in those who are normative or privileged in most senses. In Chapter IV, I pointed to various issues and communities that are excluded from the psychosocial disability discourse—substance abuse and addiction, the specific forms of political distress from militarisation and occupation, and distress stemming from religious or caste oppression. As is obvious from the list, these exclusions target people from multiply marginalised communities. This stems from, and results in, the internalisation and perpetuation of the oppressive systems and structures which shape broader society by and within the psychosocial disability movement. This section focuses on the specific tactics used to exclude certain people and issues from the realm of psychosocial disability activism and the effects it has on the people who are excluded.

##### **6.4.1 Tactics of exclusion**

My interlocutors, all of whom are engaged in an intersectional disability politics, have been at the receiving end of exclusionary tactics and describe their observations and experiences in the interviews. Some describe being told straightforwardly “that’s a no-go area” when they wanted to talk about Kashmir (*Tara*) or simply ignored when they raised issues related to the Northeast (*Anita*). For the most part, my interlocutors discussed insidious ways of excluding meaningful actions and conversations—one, arguing that some issues are too divisive; two, benevolent othering; three, co-option and dilution; four, a performance of righteousness; and five, tokenism. First, as is common within many movements, my interlocutors report being told that bringing up issues of multiple marginalisations is divisive and undermines the cohesion of the movement (Bell, 2006). There are many examples from across movements of people using their own

marginality to marginalise others such as white feminism's reaction to issues of anti-racism and trans-inclusion (Phipps, 2021). The argument for group cohesion at the expense of people facing multiple marginalities protects those in powerful positions from having to examine their own complicity in oppression. Issues that challenge the position of marginality from which leaders stake their claim as well as issues that draw attention to the privileges these leaders hold are often sidelined. The movement does not want to speak about casteism and/or religious minorities. Unable to see themselves as being embedded in a system which both marginalises them and privileges them—as a Savarna psychosocially disabled person—these conversations take place either in anti-caste movements or not at all.

...*disability enough problem nabin hain kya*, why are you bringing this? [isn't the problem of disability enough, why are you bringing this?] (*Shampa Sengupta*)

...we got one target on our back we don't want two (*Tara*)

...something that she said is within the disability movement they are just like, don't be divisive, like don't bring in these things, whether it's taking political stances around Kashmir or whether it's about caste, uhm, that's divisive... disability is something that's common to us, besides that go your own way. (*Tara*)

Second, *Chandra* used the term 'benevolent othering' to name what several other participants described. Benevolent othering is a way to understand “discourses that are ostensibly positive... but that re-inscribe structures of subordination” (Grey, 2016). *Chandra* at the time was an intern in an organisation led by an influential cishet Savarna activist and described that through the voyeuristic gaze of the leaders, the struggles of queer people and Muslim communities in the organisation were valorised but without any solidarity-based intersectional action.

There was a lot of fetishisation of queer people, this othering, there's like 'you know queer people they're this they're that Oh my God, how wonderful.' And I don't want to hear 'Oh my God, how wonderful' I want to know what you're doing?... And like almost pedestalsing, like a very benevolent patriarchal gaze... like you are almost pedestalsing but also take away their rights. (*Chandra*)

Third, some participants described a co-option of the concept of intersectionality and its diluted practice. For *Tara*, this comes about because “people in position of power and privilege” are the “guardians of intersectionality” i.e., they decide what it means and what it should look like. This co-opted and diluted version of “intersectionality” is often practiced by elevating one person who is seen as embodying that intersection. For *Naina*, the lack of an “issue-based analysis”

rather than the type described above is because disability organisations “don’t have the bandwidth to actually go into the depth of what intersectional issues really are”. This is what Angela Davis meant when critiquing social movements’ loose use of the term intersectionality stating that the term is “expected to do the work that those using it aren’t willing to do” (Davis, 2019).

Fourth and relatedly, many participants critiqued what they called the ‘performativity’ of the psychosocial disability. By performativity or performative action, they do not mean it in the Butlerian sense, but rather they are referring to the usage of radical language without radical action (Butler, 1993). Interviewees point out that mainstream organisations and their leaders make outward claims of being committed to anti-ableism, intersectional action, and building community while at the same time, reprimand or ignore members of the organisation who want to action those values. *Chandra* and *Roop*, who work closely with each other, pointed to social media and how leaders use it to learn and signal the “language of politics” and “turn[ing] everything into content”. Others point out that performative use of certain language is linked to politics of funding and visibility:

You are just leapfrogging and saying the word “disability justice” because you will get funds from some fancy international organisation. But in fact, you are doing damage, because you are not building anything, you are just profiteering from the discourse.  
(*anonymised*)

And the performance of righteousness is required because that’s what gets you funding.  
(*Aman*)

The disconnect between what is said and what is done, while well-known by those who are familiar with the psychosocial disability movement, has a devastating and real impact on people who are not in the know. *Raya* describes how a physically disabled woman struggled to come to a conference in Delhi hoping and expecting that she “will be heard here and something will happen if I speak here”. Speaking with a sense of guilt and resignation, *Raya* reflected that “we fail that hope every day” because of the vast chasm between what is presented and what is actually done.

Finally, my interlocutors spoke at length about a tactic which will be familiar to anyone who has attempted to push for meaningful inclusion within a system—tokenism, i.e., the perfunctory inclusion of one or a small number of marginalised persons, often in service of an inclusive image without any structural change. Every single psychosocial disability activist is familiar with

this—being the only and often last-minute addition to a mental health panel or consultation. Interlocutors bring up how *within* the psychosocial disability movement, dominated by “upper caste folks”, caste is brought up tokenistically:

Caste would often only be picked up as a conversation or a discussion when it was used for some sort of a token, or it was used to show that one is not casteist while in their actions they are.... no work surrounding it afterwards...I would rather take someone being honest and casteism being like, you know what, I don't care, than actually faking it at that point. (SL)

All people who talked about these methods of exclusion mentioned the role of the leadership of privileged persons and the complete lack of accountability measures in further entrenching a depoliticised and narrow way to ‘do’ psychosocial disability.

#### **6.4.2 The violent effects of exclusion**

Along with the issues and topics that are excluded from the mainstream psychosocial disability sector, people who either embody them or work on them face exclusion too. Interlocutors describe the immense emotional toll and the difficult choices they face when confronted with this exclusionary violence within a setting that was meant to be liberatory and inclusive.

First, I want to highlight the shared frustration, anger, and even despair in the parts of the interviews that address these issues. While my interlocutors and I often chuckled at the antics of the mental health or the corporate world while describing their violence, when it came to describe the violence of the psychosocial disability movement, the laughter was sparse and hollow. In many interviews, we talked about emotive and emotional things like “community” and “belonging”. I too came to psychosocial disability through a desire to find a home for my mad disabled bodymind. And when I came across the same injustice I witness everywhere within it, the betrayal hit differently; the ableism and violence in this context had a particularly bitter flavour. I found resonances of that feeling I have carried for a long time in my interviews:

I’ve always sort of struggled with a place to belong and a place to call my own. This [the psychosocial disability movement] is also a world where you have to go out there and make a name...I think that that’s been a struggle absolutely, you know?... I always felt like this lack of a sense of... belonging because I’ve always also felt that there’s been sort of this competition. (Ambika)

For me, I entered this space for my own healing. And somewhere along the way, it did heal me, but it also set me back in many ways... it felt like everything that I had built my healing on was just taken away, you know. (*Tara*)

A second effect of relentless exclusionary violence is that it presents you with difficult choices. When a place you had hoped would heal your wounds, do you stay and fight for it or do you leave and start anew?

Some, especially those who are new to the field, attempt to hold on to their ideals while also trying to fulfil funder obligations, essentially trying to do two jobs, exacerbating the already dominant push towards hyper-productivity. Others stay and try to shift the movement by engaging it, by sitting on committees, making themselves visible and heard at conferences and events. *Roop* asserted that they were unwilling to cede it entirely, saying “we *are* the fucking movement”. While this is laudable and certainly challenges the attempts to stifle multiple understandings of psychosocial disability activism, it comes with a cost. In the context of psychosocial disability, working within or engaging with a hostile and oppressive environment causes more psychosocial distress. *Roop* explains this is particularly frustrating because often their efforts are met with apathy and sometimes outright resistance.

*Ek samay ke baad mujhe laga bhi ke main toh yahaan pe let jao abhi, main yahaan pe abhi let jao aur kuchh jaise main apne ap ko maar doon, khud ka qatal kar doon tab bhi seriously nahin lenge mujhe.*  
[After a time, I felt that even if I lay down here, even if I lay down here and kill myself, even if I murder myself, they will not take me seriously]. (*Roop*)

Finally, there are some who leave the movement/sector, either by their own choice to disengage or more disturbingly because they get excommunicated from the movement. One interlocutor described their own experience “I was asked in a fit of anger to leave” (*Ambika*). Another spoke about their own as well as others’ experiences with blacklisting.

I think that there’s a lot of, like, “Either you’re with us or against us.” It suddenly gets very Sith Jedi, I mean, if you get Star Wars references... It kind of gets into a system where—I’m aware of several people who’ve experienced this kind of, for lack of a better word, blacklisting, or that sort of thing. So, I mean, it is what it is. I mean, like, there’s nothing which—yeah. So yeah, when the recording’s off. Yeah? [chuckles] (*Naina*)

*Naina* went on to say that they “would rather not get into [it] on a recorded call”. This reluctance could come from a place of not wanting to ruffle feathers, wishing to stay under the radar, or not wanting to air the dirty laundry of the movement. The last one is what keeps me up in the night.

Critical disability studies as method means knowledge production should be linked to the activist aims of the movement, but whose aims, which movement? What is the role of this thesis, much of which has turned out to be a critique of the so-called movement? I guess for me it is the belief, which thankfully at least one interlocutor expressed, that we “cannot have just one voice for psychosocial disability” that guides my decisions around this thesis.

Finally, a small number of people decided to disengage from the mainstream psychosocial disability movement and find ‘home’ in other movements. For them, the scale of the incompatibilities between their own values and the demands of psychosocial disability sector were too big to bridge and the cost too high.

We have to do some of this working to do it outside of the framework of the so-called disability movement, because that is still stuck. I don’t know where it is stuck, but it is stuck. [laughs] It is. (*Sanya*)

The desire to start anew and, as the next chapter will show, the attempts to create alternatives, is also what Dieter Rucht (2001) describes as a potential consequence of “shift from radical challenger groups to pragmatically oriented pressure organizations” which they claim can lead to a “re-radicalization at the fringes” (p. 220). It is these fringes that I wanted to start with, and what I ended up with.

## **6.5 Discussion and conclusion**

In summary, the first section of this chapter demonstrated that my interlocutors understand psychosocial disability movement/activism/activists in relation to what they think it *should be*. For them, a social movement or an activist should be grounded in the grassroots, engaged with other movements, embrace intersectional politics, and have common goals and shared identities which drive their work. In contrast, they characterise psychosocial disability settings as being overly focussed on a depoliticised version of identity politics, prioritising individual visibility over mass mobilisation, and operating in urban-centred elite siloes. The second section unpacked how processes of NGOisation, donor demands, and their neoliberal logics create the perfect environment to depoliticise, individualise, and professionalise psychosocial disability. The third section built on this to show that fascism works hand in hand with the demands of neoliberalism to exclude people from targeted and marginalised communities from leadership roles and punish those who challenge the structural setup of the sector. Finally, the last section shows that individuals within this ecosystem use a diverse range of techniques to maintain the status quo exacting a brutal emotional toll on those who face exclusion and violence within it.

Throughout this chapter, my analysis found four recurring themes which this section will focus on—one, the links between identity and materiality; two, the alignment between neoliberalism and fascism; three, the role of elites; and finally, pockets and pathways for resistance. Before diving into these themes, it is critical to note that the findings in this chapter are mostly referring to a specific part—the most prominent and the most visible—of psychosocial disability. My interlocutors speak differently about their relationship to this mainstream—some distance themselves from it entirely; some assert their presence within it (i.e., “we are the fucking movement”); and most describe a changing and evolving relationship with it. One of the difficulties of research like this is that it can only provide a snapshot, capture one moment in time. The psychosocial disability landscape and the people within it are not set in stone; it has and will continue to be shaped and re-shaped as will critiques of and relationships to it.

First, and in consonance with the findings in earlier chapters, my interlocutors speak about the desire to and difficulties in ‘doing’ psychosocial disability in a way that brings together identities and material issues. They describe an ecosystem populated either by organisations and actors focussed entirely on a service delivery model providing support and filling the gaps left by a neglectful state or by those focussed mostly on questions of terminology as a way to leave behind identities of ‘mentally ill’, ‘patient’, ‘lunatic’, ‘user’, ‘survivor’.

The de-linking of a collective and shared identity from the marginal and material conditions through which that identity was forged is a challenge shared by many contemporary social movements. Some have highlighted the role of an elite class which have co-opted identity politics, leaving behind its anti-capitalist and anti-imperialist roots in order to perpetuate a shallow depoliticised form of activism (Táíwò, 2022). Some valid critiques of new social movements are used by right-wing and conservative actors to further their agenda and dismiss the concerns of any and all identity-based movements. It is clear to me that my interlocutors are not aligned with these conservative actors and do not dismiss the importance of an identity-based movement in and of itself. For psychosocial disability movements, a collective identity of psychosocial disability, in whatever form, is an important step to challenge the epistemological underpinnings of psychiatry which would frame us as flawed, defective, and at worst, non-persons. I read the concerns of my interlocutors as part of the process of forming a radical identity politics wherein “identities are developed through processes of engagement, research and knowledge-making, where challenges are raised, debates occur and modifications or transformations take place” (Novelli et al., 2024, p. 205).



Second, the emergence and solidification of a “non-collaborative, narrowly-focused, and competitive” culture of organising within psychosocial disability, bolstered by a Hindu nationalist fascist context enables and hinders certain ways of ‘doing’ psychosocial disability (Smith, 2007, p. 10). The process of NGOisation and reliance on donors and funders leads to:

observable structural change processes in the organization. Some of these important novelties are: increased individualization of power and authority, creation of structured legislative frameworks, increased control over cooperation, growth in instrumentalization of relationships, adoption of a more competitive perspective in staff recruitment, creation of salaries, hierarchical structure and division of labour. (Gonzalez, 2021, para. 5)

Within the psychosocial disability sector which has inherited a very specific structure from the global disability ecosystem, NGOisation is characterised by increasing professionalisation, depoliticisation, global networking, and power consolidation by individuals. The impact of this process and the impact of fascism on social movements and radical politics have been well-established but usually studied separately. A key intervention I make is unravelling how fascism and neoliberalism work together to exclude certain people and issues, i.e., the combination of neoliberalism and fascist forces working in concert hinders targeted marginalised communities from assuming leadership positions. Neoliberalism demands formal organisations, and fascism makes them vulnerable. Neoliberalism demands visible and prominent leaders, and fascism punishes them. Neoliberalism demands integration with international funders, and fascism makes it a liability. This level of analysis not only helps us understand the issues facing psychosocial disability through a systemic lens but also make clear that to reclaim/plant the radical roots of disability politics, it must incorporate an anti-capitalist and anti-fascist lens.

Third, while many of the issues described above are systemic, this reward and punishment *system* is leveraged by *individuals* within the psychosocial disability movement either because they do not wish to cede the power that they consolidated through it or because they align themselves with the core values of the system. In either case, there is frustration, disappointment, and a deep sense of betrayal experienced by those who are excluded/targeted by them. For my interlocutors, caste, class, religion, and urban location are the key markers of the elites within the psychosocial disability movement. These often-unmarked subject locations shape and drive the priorities of the psychosocial disability movement, dictating what it is and what it isn’t, and how it can be ‘done’. For my interlocutors and for me, there are layers to the privilege which allow/enable this type of leadership. While I and others have described them as the North within the South and

they certainly are proximate to global centres of power, these “elite spaces are often nevertheless relatively marginal within global networks of power” (Platzky Miller, 2019, p. 23). The psychosocial disability movement in India and elsewhere emerged as a challenge to the marginalisation of Southern activists within the global user/survivor movement. This complexification of who we identify as ‘elites’ and ways they work is important to “subvert or manipulate the non-profit form to serve radical commitments” (INCITE!, 2017, p. xix). Many of my interlocutors do exactly that. They leverage the opportunities within the mainstream psychosocial disability movement, challenge it where they can, and build alternatives all at once.

Finally, it is important to note that “power does not flow in only one top-down direction”, and while my interlocutors express despair, they are not led by it (INCITE!, 2017, p. xx). The problems outlined above are real and challenging, however, “while changed structures and self-interest in organizational survival may often lead to changed, deradicalized ideologies, this process of institutionalization can drive others to seek different, more contestational forms of politics and models for their movements” (Choudry & Kapoor, 2013, p. 8). Creating new knowledges such as ‘psychosocial disability as a lens’, navigating abolition vs reform vs disengagement and disability rights, and critiquing the current system of organising are all part of ‘doing’ psychosocial disability. The next chapter builds on this one to highlight other ways of actioning an intersectional psychosocial disability politics that co-exist with or form in resistance to or are entirely unrelated to mainstream psychosocial disability.

In conclusion, the mainstream psychosocial disability movement is deeply shaped by the aligned forces of neoliberal NGOisation, funding structures, and fascism which are incompatible with ‘doing’ psychosocial disability intersectionally. Some individuals within it utilise their power to further exclude and marginalise people and my interlocutors respond in different ways—some navigate this process of depoliticisation strategically and try to bridge the contradictions presented by the system and others find it too risky or violent and try to build their disability politics elsewhere. Psychosocial disability may not be a movement and the people in it may not be activists according to common definitions of activism and movements. However, and in the words of *Falak*, “stuff is happening” and in the next chapter, I will detail the strategies of resistance and collectivities that my interlocutors embrace and build outside of mainstream psychosocial disability.

*Interlude*

*But of bliss and glad life there is little to be said, before it ends; as works fair and wonderful, while still they endure for eyes to see, are their own record, and only when they are in peril or broken forever do they pass into song.*

*(Tolkien, 1977, p. 104)*

...

शर्त लगी थी खुशी को एक अल्फ़ाज़ में लिखने की  
लोग किताब ढूँढ़ते रह गए हमने दोस्त लिख दिया<sup>60</sup>

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<sup>60</sup> Sourced from the interwebs, author unknown to me.

## **VII. “*dekho, humne dekha hain ek sapna*”: breathing crip utopias into existence**<sup>61</sup>

*dekho, humne dekha hain ek sapna* [Look, we have dreamed up a dream]

*Chandra*'s line stayed with me long after the interview. I found myself mulling it over, turning it and twisting it as I thought about the interview. A version of it is deeply familiar to me, it comes from a Bollywood song (*dekho, maine dekha hain ye ek sapna* [look, I have dreamed up a dream]) popular in the 1980s (Burman, 1981). The song is about a couple in a romantic relationship planning for their future together and singing to each other about their dreams of a home, love, and flowers. The turn of phrase *Chandra* used is slightly, but significantly, different. They use the collective word *humne* (we) instead of singular *maine* (I). We may not speak the same dialect of Hindi, may not have the same pop culture references, and the collectivity I am reading into this one phrase might not be what they intended, but the phrase stuck with me. It perfectly encapsulates the thread that runs through this chapter—psychosocial disability as a collective dream.

Much of the previous chapters analysed things that do not work, things that throw up constant contradictions, things that force compromise and sometimes complicity. In this restraining environment, created and supported by the interlocking oppressions of capitalism, casteism, ableism/sanism, and other marginalising systems, pathways to resistance and change seem few and far in between. As I write this chapter, the genocide in Gaza is escalating; the conditions caused by wealth inequality in the UK are rapidly deteriorating; fascism in India continues its onward march; and news of climate catastrophes is ever present. The worlds we dream of seem to slip further and further away. This despair was sometimes reflected back at me in my interviews. However, intermingled with feelings of powerlessness, despair, and betrayal, there were dreams of radically different worlds and a commitment to breathing those worlds into existence through experiments with everyday actions of care and collectivity. This chapter is a record of, and testament to, that fire that continues to burn even if it is sometimes reduced to embers.

My topic guide was largely based on traditional ideas of activism and movements. It focussed, like the literature, on campaigns, organisations, and legislative change. Despite this, the idea of everyday resistance, the small actions that live out the revolutionary dreams of participants, and the ways they experiment with doing this collectively came up often. In this chapter, I argue that

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<sup>61</sup> The title of this chapter is a quote from my interview with *Chandra*.

my interlocutors ‘do’ psychosocial disability by dreaming up crip worlds and breathing life into them through everyday actions. They embrace an ethos and practice shaped by experimentation, uncertainty, and mess, and in the process generate new knowledges. I share a lot with my interlocutors but am also separate from them. This is reflected in my changing use of “we”; “they”; “I” in my analysis of their words. This chapter, more than any other in the thesis, is where the commitments which inform me align with those of my interlocutors and as such, it often uses the word “we”. However, I also use ‘I’ to acknowledge that despite the many alignments between me and my interlocutors, I am the author of the text and as such, I am responsible for the analysis and conclusions within it.

In this chapter, I ask and answer how psychosocial disability is ‘done’ despite/alongside/outside the mainstream movement and what possibilities, futures, and pathways lie within psychosocial disability activism at the margins. It draws on diverse traditions of scholarly and activist thinking—utopian dreaming (Kaba, 2021; Muñoz, 2019); prefigurative politics (Raekstad & Gradin, 2020); generative power of experimentations, failures, and negativity (Halberstam, 2011; Sebatindira, 2023; Smilges, 2023); and the role of hope in our political action (Kaba, 2018; Muñoz, 2019). It is a messy chapter and is intentionally written that way to reflect the realities of my participants’ work. It does not provide a comprehensive framework to do activism in a different way. It is written as a reflection of the argument it proposes—embracing uncertainty, messiness, the partial, the provisional is itself a form of disability justice activism, one that rejects a one-size-fits-all approach.

Drawing on concepts of utopia and hope from queer and abolitionist thinking, the first section focuses on the kinds of utopias my interlocutors dream of. The rest of the chapter follows these threads to focus on the everyday work of living those dreams. The second section highlights why and how my interlocutors set up collectives as a way of organising. Section three explores how an insistence on existence as a complex and contradictory being in a hostile world can reshape our understandings of what counts as resistance. Section four continues the focus on everyday practices and small actions which my interlocutors practice in their lives and the new meanings of bodily autonomy, care, and access which emerge from them. Overall, I argue that their attempts at democratisation, power redistribution, accountability, care, and access are a form of prefigurative politics, i.e., “an experimental implementation of desired future...[and] practices in the here-and-now” (Raekstad & Gradin, 2020, p. 10). My interlocutors attempt to live their utopian worlds with the full knowledge that they might fail in their experiments and may not realise their dreams in practice, but they view their ideal worlds as worth ‘failing towards’ (Sebatindira, 2023). The final section steps back to reflect on the elements underpinning these

crip dreams. I conclude that through the practice of bringing *crip utopias* into existence, my interlocutors disrupt imagined binaries and boundaries between seemingly dichotomous concepts—between success and failure; between the everyday and the structural; between grief and pain, and hope and joy; and between the present and the future.

### **7.1 Dreaming utopia in a hostile world**

When we think of movements and when we think of resistance, we need to focus on things that we love, and that will provide a much more sustainable hold and reason than hate would. And I still think about that a lot...we really need to change that lens and focus on what we love and fight for that, rather than fight against something else. (*Raya*)

This quote suggests that sustained resistance requires a focus on what we love and fight for. For me, this sentiment begs the questions: What is the future we fighting for? What do we dream about? What can these dreams tell us about the worlds we inhabit and the worlds we want to inhabit? And how do we maintain hope in the face of the brutal worlds we live in? My interlocutors undertake their actions within the context of their dreams for a future world. To understand the implications and significance of their work, in this section, I focus on three themes which recur throughout this chapter—one, I examine the contours and content of the utopian worlds my interlocutors dream of; two, I highlight the collectivity which underlies these dreams; and finally, I underline the generative tension between their hope for utopian futures and their disappointment with the harsh realities of the present.

First, and in large part because so many people use the words ideal worlds, future dreams, and utopian thinking, it is critical to closely examine what the nature and content of my interlocutors' utopias are. The central feature of utopian thinking in fascist and eugenicist dreams is the elimination of the 'undesirables' including queer and trans people, disabled people, people of colour, and religious minorities (Crone, 2024; Fitting, 1991). Disability activists and scholars are wary of the concept of utopian thinking because it is so often represented as a world without disability (Mackey, 2009). Even within the ideal situation presented by the social model of disability, disabled people no longer exist because societal barriers which create disability do not exist. Equally, utopian dreaming or utopian imagination features heavily in abolitionist and queer thinking. In these traditions, it is essentially a rejection of the here and now as immutable and unalterable and an "insistence on potentiality or concrete possibility for another world" (Muñoz, 2019, p. 1). The *insistence* on the possibility of different futures includes working towards those futures in the present. Further, *concrete* possibilities locate these utopian futures within the realities

of past and present struggles for justice. It is this tradition of utopian thinking which I, and my interlocutors, align with.

Building on the insights from my interlocutors who employ psychosocial disability as an intersectional lens, I understand *crip utopias* as dreaming about worlds without discrimination and violence against disabled peoples but equally worlds without fascism, casteism, militarisation, colonialism, and capitalism. In their articulation of “ideal worlds” or utopias, my interlocutors not only reject the idea that oppressive social structures are natural or immutable but also see them as inherently interlinked and interconnected (Turner, 1980).

The utopian dreams of my interlocutors are radical and revolutionary insofar as they imagine worlds not just without ableism, but also worlds without exploitation and violence stemming from capitalism, fascism, casteism, and patriarchy. For instance, *Chandra*, drawing on her work with prisoners as a researcher, refers to building transformative and abolitionist justice mechanisms in place of the punitive criminal justice system, stating explicitly that she sees these issues as interconnected with psychosocial disability justice. Both *Chandra* and *Shampa Sengupta* speak of an inclusive “ideal world” which would accommodate not just psychosocial disability but differences of all kinds.

See in an ideal world, we would understand [psychosocial disability] as a spectrum. And that everybody is going to fall in and out of that spectrum at some point. Some people will stay on it for much longer, and so ideally, what I would want is a kind of world which can accommodate all of this. (*Chandra*)

...in the ideal situation should be there should not be any discrimination at all. (*Shampa Sengupta*)

...imagine a future where crip time *hain*, individual *ke bhi hain* but collective *ke bhi hain*. [Imagine a future with crip time, both for the individual and the collective]. (*Roop*)

Second, participants describe these aspirations in a collective context, i.e., in relation to organisations, friends, peers, colleagues, concepts, and texts. For instance, two of my interviewees specifically refer to Disability Justice frameworks (Berne, 2015). They acknowledge that the frameworks are not yet in practice in India but nevertheless they incorporate the principles of Disability Justice into the future they imagine. I will return to Disability Justice frameworks in the last section of this chapter.

I would say I know the Disability Justice space only theoretically and only through the work of like stuff like Sins Invalid and like I love the posters that they do and a lot of

very global north stuff... I feel like Disability Justice would allow, especially in India, for conversations to happen on intersectionality and on passing the mic to people who have not had their voices heard or who are, even within this space, spoken for. So, you know it might be a very hopeful dream. I told you every time I enter a space; I am very enthusiastic and then I'm always disappointed and crushed. (*Anita*)

Several activists and scholars have touched upon the significance of *collectively* imagining a radically different future within social movements (Kelley, 2002; Platzky Miller, 2019). It is a key theme in Black, feminist, queer, leftist, and anarchist thought and action (Graeber, 2002; hooks, 2009; Muñoz, 2019). Within disability movements, Disability Justice is not just a framework for activism, but is also a “vision born out of *collective* struggle” (Berne, 2015) (emphasis added).

Robin D.G. Kelley (2002) in their examination of Black radical activism argues that “revolutionary dreams erupt out of political engagement” (p. 8). Similarly, exposure to new ideas as well as relationships with fellow activists is a key element in my interlocutors’ imagination of a radically different future.

Finally, my interlocutors’ hopes for and dreams of a just world exist alongside the disillusionment and difficulties they face within the psychosocial disability movement and elsewhere. In this way, my interlocutors follow Muñoz (2019) in his conceptualisation of “concrete utopias” (as opposed to “abstract utopia”). He highlights that concrete utopian thinking is rooted not in “banal optimism”<sup>62</sup>, but rather in “the realm of educated hope” and what others have called “critical hope” (Kaba, 2021, p. 3). Educated hope is that which “is grounded” and “is cognizant of exactly what obstacles present themselves” in our work towards our utopian dreams (Muñoz, 2019, p. 207).

For my interlocutors, utopian hopes exist side-by-side with disappointment and disillusionment with mainstream psychosocial disability. This hope does not emerge from disillusionment and disappointment, i.e., disillusionment and disappointment do not turn into hope. Rather all exist together. *Deepu* expresses both the dream of radical inclusivity responsive to everyone’s particular needs, and the disjuncture between this dream and current practices of organising:

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<sup>62</sup> Muñoz (2019), building on Ernest Bloch’s conceptualisation of different types of utopias, makes a distinction between concrete and abstract utopias. Abstract utopias, for Bloch and Muñoz, are de-linked from historical consciousness and hence have a limited ability to bring about collective political transformation. Abstract utopias are built on ‘banal optimism’ which is untethered from historical and current obstacles and as such, constitute not much more than wishful thinking (Muñoz, 2019).



If we decided right from the start that...the norm is inclusivity, not based on charity, not based on ‘because this person needs help’, but that’s the way it’s going to be, then there is no problem. So then if you’re mad, you’re part of that conversation. If you are paraplegic, that’s part of your conversation. If you are autistic, that’s part of your conversation. We have to figure out ways to do it. I don’t think we are taught that and therefore it becomes more and more complicated for us. (*Deepu*)

Thinking about and enacting hopes and dreams alongside disappointment sustains the possibility of transforming existing worlds and work towards those dreams. Just like mainstream psychosocial disability movements did not live up to their liberatory potential, these radical fringes of the psychosocial disability movement might fail to do so in some ways. By speaking about hope and disappointment together, my interlocutors hence demonstrate that “hope is work; we are disappointed; what’s more we are repeatedly disappointing each other” and that the failures to always live up to these dreams is “neither the cancellation of grounds for hope, not a discharge of the responsibility to work to change present reality” (Muñoz, 2019, p. x).

In this way, dreams are not presented in a vacuum divorced from the socio-political realities of the present. All participants are cognisant that there is a need to navigate the harsh realities of the current world and engage with tools and mechanisms which cannot deliver justice but are nevertheless important to survive in the world. Many activists and scholars have dismissed the radical dreams of psychosocial disability activists (for instance, abolition of coercion in psychiatry) as wishful thinking and unrealistic (Freeman et al., 2015). When *Roop* acknowledges “*wob revolution [kal] tob nabin aa raba, dheere dheere aa raba hain* [That revolution is not coming [tomorrow], it is happening slowly slowly]”, they are situating their revolutionary dreams within the reality of slow and small changes.

In conclusion to this section and to set up the rest of the chapter, I argue that my interlocutors engage in a form of utopian imagination in the tradition of queer and abolitionist thinking—they collectively dream of a future world where all axes of oppression are erased; and equally, they situate their dreams within the oppressive realities of the present world. For them hope and disappointment, and the future and the present live together and more so, are contingent on each other. I will continue exploring this theme within the rest of this chapter which focuses on the things we (the people invested in justice-based worlds) do, the things we want to do, and the things we cannot do to create the worlds we dream of.

## **7.2 Experimenting with, and acting through, informal collectives**

My interlocutors breathe life into their utopian futures by rehearsing and practicing them in the present. They ‘do’ their psychosocial disability justice dreams collectively in the here and now espousing an ethos of prefigurative politics. Prefigurative politics is an extension of utopian dreaming, it is the act of living in the present as if the future you dreamed of is already a reality (Cornish et al., 2016; Davoudi, 2023). It is an assertion that the process is as important as the goals (Bevin, 2023). For abolitionist organiser Mariame Kaba (2021), this requires an openness to “a million different little experiments” and being “open to failure” (p. xxvi).

For my interlocutors, the pursuit of collective dreams calls for ways of organising which espouse values of democratisation and accountability. Towards that end, they describe their experiments with working through informal collectives, often contrasting them to the NGOisation of the mainstream psychosocial disability movement. Some of my interlocutors have created and are part of informal disability collectives; others have engaged with them only intermittently; and some have only encountered them briefly in disability, queer, leftist, and feminist activisms. All referred to them in some way or form. But what do my interlocutors mean by informal collectives? What forces led them to forming them? What kinds of action and activisms are enabled by/through collectives? How does power circulate within these non-hierarchical collectives and how do my interlocutors navigate that? How does this way of coming together fit into the broader concerns folks have vis-à-vis organising? To answer these questions, this section has three sub-sections—one, why people form collectives; two, the challenges they face with this form of organising; and three, the role of collectives within broader movement building. I conclude that my interlocutors engage in crip organising through a series of creative experiments to actualise their collective dreams in the here and now.

### **7.2.1 Forming collectives to survive the ‘now’ and build the ‘then’**

The drive to form collectives, in part, emerges from the need for protection against state repression; as a response to the hierarchies and neoliberal logics of the mainstream psychosocial disability movement; and from a desire to enact crip politics. This mix of reasons reflects the co-existence of a need to survive, a disappointment with the current state of affairs, as well as a desire to work towards utopian dreams.

First, for people working with groups and on issues at risk of repression by the state, a collective becomes a means of evading state violence. According to my participants, a collective allows for easy dissolution in the face of state targeting and for its members to disappear and reappear in

different formulations. This is a tactic that several groups within India and those organising in similar repressive environments have undertaken (Platzky Miller, 2019). Furthermore, it becomes a way to continue work they want to do without the strings that risk-averse funders come with, something which *Roop* in the quote below calls “freedom of speech”. Two participants, both Dalit queer disabled persons, explicitly mention state violence and repression as a significant reason in their choice to form a collective rather than a registered organisation, with *Roop* saying:

We're doing the work, but I think because of the safety reasons and because of our freedom of speech, we didn't want to become an organisation... at any point of time, if anybody has a problem with it, right, so it's easy to disappear. (*Roop*)

A second reason underlying the drive to work within collectives is the desire to create ways of organising which are not characterised by formalisation, professionalisation, and institutionalisation. Collectives, for my interlocutors, emerge from a rejection of institutionalised hierarchies and a desire for the democratisation of power. *Bhanu Priya* explicitly mentioned the process of registration, including the requirement of hierarchical structures such as “board members”, as a key reason for forgoing the establishment of a formal organisation. For them and others, building a group with a flat or horizontal structure offers the chance to experiment with different ways to democratise power, expertise, and decision making. *SL* has worked for MGMH organisations, psychosocial disability NGOs, disability collectives and a freelance artist compares her experiences across them:

In the alternative organisations that I've been part of... often the discussions seem more democratic there and they also seem respectful of people's feelings and opinions. And there's a back and forth or even sometimes a debate done really respectfully, versus some organisations where I think there's more of a defensiveness when certain things are spoken. (*SL*)

Despite the advantages of horizontalism described above, detractors of this strategy point out that it is difficult, if not outright impossible, to practice true horizontalism because in the absence of formal power structures, informal structures emerge to vest power in a small group of elites (Bevin, 2023; Freeman, 2013). While my interlocutors continue to pursue collectives which espouse the values of democratisation and power sharing, they acknowledge that there is no straightforward one-size-fits-all solution. Their search for and experiments with forming collectives are provisional and a work-in-progress. For instance, *Bhanu Priya* while giving examples of projects, discussions, and priorities that came from members of their collective,

describes their attempt at creating “a democratic space” where “there is no one decision maker”. However, they also go on to acknowledge their own informal role as a decision-maker:

I won't say there is no decision maker, I am the one making decisions, I'm the one making the plans, but I'm also running them through people. And other people are also thinking about which direction the collective should go. So, their interests are equally important, and like what all should be included in the collective, or what all should we do next? (*Bhanu Priya*)

Similarly, *Roop* provides an example of consensus building within their collective, but they too go on to acknowledge that this model of decision making was only made possible by the small size of their collective and might not be possible in larger groups.

We won't pass anything unless everyone agrees... it's not going to be like a majority vote where [if] three people are in agreement but two people are not, we're going to pass it. Whereas consensus, like, even if those two people disagree, then we do something that makes them agree also, right? So, we bring everybody into the fold. It was a horizontal show of power. (*Roop*)

Finally, and despite the difficulties of practicing horizontalism, my interlocutors highlight that collectives enable them to enact their crip politics and hence bring their crip futures into the present. Challenging the demands of hyper-productivity, several participants talked about the need for workplaces in the activist ecosystem, and indeed the world, to be more flexible and accommodating in their timelines. *Roop* mentions that they did not want the “9 to 5” where you “need to do certain things [a] certain way” and goes to say that forming a collective allows them to create a way of working and being which emulate the dreams of the accommodating future worlds outlined in the previous section.

*Hum [redacted] main yeh karna chahte the ke aap usko [politics] jiyoge kaise. Agar hum crip time bol rahe hain toh woh workshop main kaise lage ga, how can we imagine a future where crip time hain, individual ke bhi hain but collective ke bhi hain. Toh hum pehle aisa karte the ke kabhi bhi, hum usually toh hamare paas ek gadda bhi hota hain, hum bolte the app so jao agar sona hain, apni dawaaiyan leke aana, we can have a medicine break. [What we wanted to do [in our collective] is how will you live your politics. If we are saying crip time, then how will that look in practice in a workshop. How can we imagine a future where there is crip time, for the individual but also for the collective. So, we used to meet, and we would have mattresses*

where we meet, and we would say if you want to sleep, sleep; if you need to take your medicine, we can have a medicine break]. (Roop)

The quote above provides an example of how collective dreams (in this case, crip time) are ‘done’ in the present (in this case, sleep, mattresses, and breaks). In this way, and within this example of living and working on crip time, *Roop* and their fellow collective members are engaging in prefigurative politics—they are living as if the crip utopias they dream of are here already, and in doing so are actively building them (Piepzna-Samarasinha, 2022; Rackstad & Gradin, 2020). Melting the borders between a future then and a present now is an essential component of crip utopias. I will return to this in the discussion section.

### **7.2.2 Experiments in accountability: navigating power relations within collectives**

As discussed in the sub-section above, forgoing the hierarchical structures of a formal organisation in favour of informal collectives does not erase the ways power circulates within organising. Forming and maintaining mechanisms for accountability is repeatedly mentioned in my interviews as a key aspect of navigating power imbalances and the potential for abuse of power. This sub-section highlights three key points—first, the project of navigating power and its abuses is constant and ever-evolving with many pitfalls; second, I present the attempts my interlocutors have made at building accountability methods, the problems they face, the ways they think about concepts of forgiveness and resolution; and finally, I underline that these practices must always be situated within the specificities of their context.

First, organising by forming collectives, for many participants, is a constantly evolving process. Their attempts to address issues of power and accountability can be understood as a way of experimenting, one which embraces the idea that failure is generative, i.e., failure opens new pathways and possibilities (Halberstam, 2011; Sebatindira, 2023). My interlocutors do not present their methods of accountability within collectives as a polished and finished framework, rather they describe a “work-in-progress” (*Naina*) and a process that is “still evolving” (*RP*). For them, utopia is not a place you reach at some point, rather it is something that must constantly be built or as *RP* says in her poetic and evocative style—it is an endless act of weaving stories.

We don’t have kind of a standard operation, but there are basics. You know, the way we function, I still haven’t put it on paper. It’s still evolving. It’s still evolving because we are learning with every person. I don’t think this is ever going to end. It’s always going to be an experiment...So as the narratives develop, the project also develops, you know. We

keep weaving the cloth. We're just weaving the story and it's endless. I guess it's endless... (RP)

All interlocutors are clear that a statement of or even an attempt to form a non-hierarchical collective does not erase power imbalances or implicit leadership structures within the group. For instance, even the decision to form an organisation or a collective or any other form of structure is one that is often taken by a single person or a small group of persons. An implicit hierarchy, where some members of a collective see a specific person “as the boss” (*Roop*), may be formed. This requires continual vigilance and mechanisms of accountability to ensure that power is not misused.

Second, to deal with instances of power misuse and harm, my interlocutors experiment with various norms and informal mechanisms of personal and community accountability. For some this starts with the explicit and repeated statement that every member of the collective is fallible, i.e., every person has the potential to do harm to other members. *Chandra* describes that within their collective, accountability for harm is a constant part of the debate. Members lead by example, holding others accountable by pointing out what went wrong, the subsequent harm, and often passing on resources to the person being held accountable in order to constructively address the harm.

I know if I fuck up, I will be held accountable, and I'm OK with being held accountable. I know somebody will come after me if I fuck up in certain areas. The same way that [other] people in the collective know that I will do the same and isn't that also a promise of accountability, right? (*Chandra*)

While the need for some form/mechanism of accountability is clear, the “promise of accountability” is not always straightforward to implement. For my interlocutors who work at the intersection of multiple movements and hence alongside people from different caste, class, gender, sexuality, and religious locations, they must navigate the differential and shifting dynamics of privilege and power. How one navigates mistakes, comments, and actions which perpetuate oppression, or as *Chandra* puts more succinctly “fuck-ups”, whether within a disability group or within the context of building alliances and solidarities is something which many people refer to.

For some, like *Madhu* who is a senior activist running their madness-focussed organisation for several years, there are no red lines. *Madhu* states that if someone shows a willingness to listen, they will work with them. Others are more elaborative and draw on concepts of transformative

and restorative justice<sup>63</sup> to explain their positions. *Shivangi Agrawal* talks about accountability in reference to working with casteist people or people who make casteist remarks. They frame this as a question of how we understand forgiveness within collectives and movements. On one hand, they say that they believe in “forgiveness and conflict resolution” but on the other acknowledge and express their frustration with a state of affairs wherein “upper caste people or Hindus...just say shit [unapologetically] and there is no consequence ever.” They further describe a split between “two parts of me”, one which wants to “work towards forgiveness” and the other which is led by “anti-caste activists who have said that it’s not possible to work with privileged upper-caste folks”.

*Shivangi Agrawal*, along with a couple of other participants, invoke “transformative justice” to navigate this tension, arguing that forgiveness must work alongside “resolution and accountability” (*Shivangi Agrawal*). Forgiveness for them does not function as permission to continue to behave badly, but rather as part of a series of actions which both address the harm caused and demand a change in the actions of the person who caused the harm. This framing of forgiveness is rooted in understanding mechanisms of accountability in relation to power, the necessity of a set of shared values, and the need for adapting responses to the particularities of the situation. For instance, *Aman* makes clear that they are willing to “give [some] people the time to make their mistakes” but if the person causing harm is someone who is a powerful employer with a “a fancy, diversity, equity, and inclusion team” and “have raised five hundred million dollars”, they would take a more punitive approach or as they put it in their hyperbolic style “roll up my sleeves and punch you in the face”.

Finally, *Raya* makes sure to emphasise that any form of transformative justice-based accountability cannot have a one-size-fits-all approach. They distinguish between a “disagreement in values versus disagreement in strategies” and go on to say that forgiveness and accountability can only work “if your basic values are clear”, i.e., if everyone is fundamentally committed to a set of foundational principles of justice. Experimentation and failure for *Raya*, as

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<sup>63</sup> Both restorative justice and transformative justice are non-punitive and non-retributive means of addressing harm. Restorative justice seeks to create a collaborative process between the perpetrator of harm, the victim of harm, and the broader community to address the impact of the harm and restore relationships. Transformative justice also seeks to address harm in a non-punitive manner but beyond the individual act, it seeks to transform “the culture and power dynamics of the community” as well as the broader structural forces which enable harm (Bonsu, 2020, p. 50). In this way, transformative justice is “militantly against the dichotomy between victims and perpetrators” (Kaba, 2021, p. 149). For more refer to Kaba (2021); Dixon & Piepzna-Samarasinha (2020); and Nocella (2011).

it is for Kaba (2021), is generative only when the members of a collective are united on certain foundational principles.

You can't be like *achha humne yeh bana diya, ab hum isko hi follow karenge* [okay we have now made this, we will only follow this]. With every situation, you need to think. And that's meticulous, but I think that is part of what is required, right? So even within solidarity, when we talk about disagreements, we need to really look inwards and at the same time look at structural issues; and look at how to navigate disagreement in values versus disagreement in strategies, and whether or not we can bridge that gap with people. (*Raya*)

The point of outlining these tensions and contradictions is not to prescribe one way as the correct way to do accountability, neither is it presented as such by my interlocutors. Anyone who has worked in any capacity in activism knows all too well that accountability and justice are a projects-in-the-making and require careful and meticulous thought (*Azaad*, 2024). *Chandra* said of their work "it's a collective that's evolving, and we are also learning as we engage with people". In conclusion, experiments in navigating power dynamics within collectives requires constant and adaptive practices of thinking and doing collectives.

### 7.2.3 'Crippling' collectives and reconfiguring movements

The role of collectives within broader movement building, what this way of organising would mean, and what it would require from us came up only once or twice in the interviews but is critical to highlight. *Raya*, who has worked within many different types of organising (leftist political parties, unions, small collectives, loosely connected movements, and formal NGOs) stated that there is a pressing need for many "smaller collectives" that work together. This is a departure from how the psychosocial disability sector currently works, which is focussed on expanding an organisation, incorporating other organisations or groups within its remit, and hence further consolidating control over power, funding, and discourse. What *Raya* is suggesting is a more decentralised method of organising. Further, they emphasise that redistribution of power is a key part of this way of working, both in terms of not "gatekeeping information" as well as not seeking or holding onto the "limelight". Speaking more generally about movements and organising they say:

I think we need to be okay in being faceless cogs in a movement, right? ... So that when we get burnt out, somebody can also fill in that space. I think that kind of mobilisation is the way how to go, right? Where everybody's responsible and nobody's responsible,



right? Where we're okay to step down the moment we think that 'Okay, this is getting too much and somebody else can step in'. (*Raya*)

They were not talking specifically about disability action but there is something deeply crip about this way of thinking about activism and movements. While this form of decentralised and leaderless organising has been criticised for its historical inability to bring about radical change, analyses of methods of organising has rarely used a disability lens (Bevin, 2023). Activism within mainstream human rights literature, as outlined in the previous chapter, is often equated with consistent and tireless action. That consistency and tirelessness is simply not possible given the realities of life as a psychosocially disabled person. What *Raya* is pointing to, in my opinion, is a radical crip way of organising. It is what collectives would mean beyond simply a way of structuring our activism. It is re-imagining the collective in collective action using crip terms. The collective in crip terms is much more than a group of individuals, rather it is process built on crip principles which enables people to step back as and when they need or want to, without halting the broader work of the collective. As abolitionist and other justice-based organising remind us, within the context of constant and multiple urgent crises that require our attention, the increasing workloads and precarity we live with, and the consequent exhaustion and illness, building any activist endeavour on the crip principles of rest and/or non-action is critical for us and our movements to survive.

In conclusion, for my interlocutors forming collectives is both a pragmatic strategy (i.e., evading state violence) and has ideological elements (i.e., democratisation, decentralisation of power, crip activism). Collectives not only provide settings to enact their politics and dreams, but the very act of forming collectives is an enactment of their dreams and aspirations. Through a rejection of structured forms of coming together (i.e., NGOs) they are embracing an ethos of experimentation and acknowledging that failure is a part of that process. For instance, ideas and mechanisms of accountability are continually being reflected upon and debated within a collective.

For my interlocutors, the provisional nature of what we do and what we can do, does not take away from the work, but is in fact the work itself. *RP*'s comment that "it's always going to be an experiment" reminds me of Kaba (2021) and the work of One Million Experiments<sup>64</sup>. When my participants experiment with forming collectives and accountability mechanisms, that is this work. The work of living our liberatory dreams—abolitionist, disability justice, anti-colonial, and

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<sup>64</sup> One million experiments website: <https://millionexperiments.com/>

all other liberatory work—is always provisional and necessarily trying something and failing and trying something else and then again and again and again. Breathing life into crip utopian dreams necessarily means breaking the dichotomies of the present and the future—practicing our future dreams in the present—and between success and failure—failure is built into our experiments of utopia, and it is generative.

### **7.3 Existence is resistance**

Crip life invites us into fierce creativity. Because the world continues to treat us as worthless, creating new worlds is a matter of survival for us. Dreaming is a matter of survival (Berne, 2021, p. 9).

‘Existence is resistance’ is a political statement and sentiment used by many marginalised people and communities who have faced genocide, exclusion, and erasure, i.e., by peoples and communities who are deemed not worthy of existence or survival<sup>65</sup> (Butler-Rees, 2023; Lakha, 2019; Wolfin, 2023). My interlocutors too referred to existence and survival in a hostile world as political action and activism. Furthermore, they seek and create frameworks and settings which can hold and embrace them in their entirety as crip and disabled and queer and as full people with complex and contradictory emotion. In this section, I first examine my interlocutors’ understanding of everyday existence, both individually and as a community, as a political act. I then go on to explore their desire and search for settings to express joy as well as grief and pain. I conclude that crip utopias do not dismiss what is often considered non-action by mainstream human rights and social movement literature, i.e., the everyday work of surviving a eugenicist and fascist world. Equally they do not create artificial dichotomies between ‘positive’ and ‘negative’ emotions, rather they hold them together.

#### **7.3.1 Re-thinking what counts as action and activism**

Chapter VI examined a particular type of activism—loud, antagonistic, ideologically rigid, with power vested in one or a small group of individuals—which is demanded and rewarded by the entire psychosocial disability ecosystem and the broader capitalist context. This section, and the next, focuses on a different type of activism, one that is often not considered activism within

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<sup>65</sup> Indigenous communities and other peoples who face ethnic cleansing and genocide such as Palestinians have long used the phrase or a variation of it to express their ongoing resistance. The phrase or the sentiments it holds is also prominent in Black liberation, queer, and disability activism. (Rana, 2025).

mainstream social movement scholarship or by society. It concludes that revolutionary actions are not always spectacular but can exist in the everyday experience of survival.

Several people spoke about how the very experience of being disabled in an ableist and hostile world requires one to be an activist or engage in activist action, whether it is labelled as such or not. This idea that “every disabled person is an activist” (*Abhishek Anicca*) was repeated by several participants as they described their everyday life navigating friendships, relationships, families, workplaces, and the world in general. My interlocutors gave many examples of this work—trying to get friends to meet in accessible spots, complaining about shops or ATMs being inaccessible, “learning about discrimination” that happens to other people through social media.

When you’re born with a kind of a disability, every step of the way you have to fight for your right to education, right to access spaces and things like that. I think from the beginning, I have seen that activism that my mum has to do, had to do when I was born...she wouldn’t call it activism, but I would. (*Shivangi Agrawal*)

For my interlocutors who face barriers and violence on multiple fronts, they described everyday existence as activism beyond the realm of disability. For a queer gender non-conforming participant, being able to change their personal appearance was an act of resistance (*JJ*). For one Dalit activist, making themselves heard in a world that demands they be small and silent, was an act of defiance. *Laila* gave an example of existence as a political act of resistance, juxtaposing it with more traditional forms of activism:

I was at the railway station with my [research] participant [who] was transitioning. And at the same time the 377 discussions were taking place. All my friends had gone to Jantar Mantar, and they were participating in the decriminalisation protests... My participant was just completely oblivious to what was happening in the same city at the same time because he was just living their lives. And by living his life he was still questioning things around him...So I think that person is, anyway, political just by who they are... but they may not think so. (*Laila*)

All the participants who refer to existence as resistance are explicit about understanding it with its full political underpinning, i.e., existence is resistance *for those who are not meant to exist*<sup>66</sup>. *Roop*, a

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<sup>66</sup> A variation of the phrase, i.e., “never meant to survive” is expressed in the poem ‘A litany of survival’ by Audre Lorde (1978).

queer Dalit and disabled person who faces violence and discrimination in several spheres of life, stated it most explicitly saying:

[I know] how joy is political, how smiles are political, you know, *ek samay ke baad aap dance kar lo, yeh bhi bhot political hain, kyunki yeh chahate hain ke hum marr jaye* [after a while if you dance, this is also political, because they want that we should die]. (*Roop*)

They all describe this work as unrelenting, constant, and as something “you have to do again and again because there’s no systemic change” (*Abhishek Anicca*). Their refusal to depoliticise or romanticise this act of everyday activism and resistance, their exhaustion with it, their desire for not having to do it, and their continual commitment to do it for as long as is needed are essential elements of existence as resistance. *Aman* refers explicitly to Audre Lorde’s thoughts on self-preservation as political warfare alongside their own thoughts on existing as a revolutionary act (Lorde, 2017). His efforts to internalise the message “my existence was worthy without having to prove it in overt ways” is a challenge to both capitalist ideas of worth being dependent on productivity as well as activist ecosystems wherein ‘non-action’ as resistance is ignored or neglected.

Not everybody can be on the front lines in the war against bigotry...but bigots would love nothing more than if you were to just disappear with all your thoughts and all your problematic annoying ideas. And I don’t want to make it easier for them...And in that sense, for the first time I understood that what Audre Lorde said could be true of me as well, and true of other people like me as well. Just existing, to me became revolutionary. It was also enormously liberating because it meant that my existence was worthy without having to prove it in overt ways. (*Aman*)

There are critiques of reifying everyday activism in the face of the proliferation of individualisation and depoliticisation of activism. Some of these critiques are founded within the context of capitalism invading and co-opting all practices. For instance, the once powerful political statement about self-care and self-preservation by Lorde is now repackaged and sold to us as spa vouchers and scented candles (Kim & Schalk, 2021). However other critiques stem from a conflation of individual action in the everyday as individualised action or of seemingly apolitical action as depoliticisation of collective action. Cindy Cruz (2011) asks, “At what point does action count as political?” within her ethnographic work with resistance practices by LGBTQIA+ youth (p. 554). This is an important question. While I have no answer to this question and do not seek to provide it, my interlocutors make clear to me that their everyday action is both collective and political.

For my interlocutors, existing and surviving as a community is inextricably linked to the everyday and subtle practice of resistance. Creating collective access, i.e., coming together in ways which accommodate everybody's needs, is a key Disability Justice principle (Berne, 2015). This is particularly profound in a world which “separates, isolates and divides [disabled people], so that we cannot move” and is designed in ways to make it hard for “disabled people to stay together” (Mingus, 2010, para. 11). Several participants highlight that a key feature of the collective they belong to is simply to come together, talk, share, and be.

*Mujhe pata ke chaar log bethke agar chai peete hain aur woh agar disabled hain ya kuch hain who bhot maiyne rakhta hain* [I know that if four people come together, drink tea and they are disabled or something, this matters a lot]. (Roop)

*Shivangi Agrawal* pointed out that it was during these intimate conversations “at home and on our beds, on our living rooms while we are eating, while we are having soup or dinner” are where political conversations about queerness and disability, take place. *Raya* used a beautiful turn of phrase “*rasoi ka rishta*” i.e., a kitchen relationship or a food relationship, which they state is a key part of building long-term sustained conversation that are foundational to movement building. *Shivangi Agrawal* also added that these conversations are critical due to the isolation of people with disabilities, both from each other and from able-bodied/minded people. Furthermore, for my participants, care, friendships, healing, and being together, are explicitly political action, which I will explore in more depth in the next section.

We are locked into our rooms and people don't want to see us. They don't want to associate with us, or they don't want to socialise with us. And I think that's why it's very important, people coming into our personal spaces and having these conversations with us, it makes a big difference. (*Shivangi Agrawal*)

In this way, through small everyday acts of survival, resistance, and defiance on individual and collective levels, my interlocutors are providing examples of how they reframe what we think of as activism and creating examples of the collective communities which would populate their future worlds.

### **7.3.2 Finding room for disabled joy, pain, and grief**

In Chapter IV, I concluded that psychosocial disability has the potential to hold within it many facets of the disabled experience, including the emotional, embodied, and visceral. I argued that my interlocutors reject the neglect of the bodymind and everything it holds within mainstream disability organising and instead desire concepts and frameworks which can hold the structural,

the embodied, and the felt together. This section will focus on how people articulate the everyday affective experience of being disabled—grief, joy, rage, love—and its entanglement with and effect on disability activism. My interlocutors talk about the emotions as part and parcel of their disability work and in this section, I explore how they understand the role of acknowledging and mobilising a disabled feeling self, with all its messiness and seemingly contradictory emotions, as part of psychosocial disability activism.

How we should feel about our disabled selves and which parts of those feelings we should express publicly changes depending on which version of ableism we are fighting. For some people with lived experience of mental health issues, whose distress was reduced to psychiatric diagnoses, it was important to express that distress in complex ways. For others with lived experience of alternate/unusual experiences, it was important to challenge the idea that such experiences are always distressing by highlighting and emphasising the almost spiritual joy and freedom of madness. For people fighting against the idea that being disabled is something pitiable and full of distress, it is important to emphasise that there is joy and pride in disability. Disability pride parades and Mad Prides are part of that tradition. For people who are attempting to undermine the ‘supercrip’, the ‘disabled inspiration porn’ stereotypes<sup>67</sup>, expressing the less than inspirational parts (the grief, the rage) of being disabled is key. For those who are focussed on changing social structures which impede access, like much of the mainstream psychosocial disability movement in India, talking about feelings is at best a distraction from the ‘real issues’. *Deepu*, talking specifically about the psychosocial disability movement in India, expressed their frustration with the reluctance of the mainstream movement to talk about the complex emotional and affective experience of disability when they say, “we don’t talk of grief, we don’t talk of joy, we don’t talk of many things”. They are referring to the contradictory and complex feelings that mad disabled lives hold and a refusal to be reduced to a singular version of that life. Many of my interlocutors were explicit that pain and grief and hate is as much as a part of their experience as community, joy, and love. *Neba* moved seamlessly between expressing joy and pain, stating “I do have disabled joy...when I am in community with disabled people” and in the very next sentences saying that “it’s frustrating to be in pain constantly”. One of the most

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<sup>67</sup> Media representations of disabled people either rely on presenting them people as objects of pity or charity or the more recent turn towards presenting them as inspirational and/or superhuman. The emergence of ‘Supercrip’ stereotype, i.e., a disabled person who is as good as or better than able-bodied people, has been critiqued by many disability scholars. They argue that supercrip or disability inspiration porn reinforces the idea that worthiness is dependent on abledness, reduces the complexity of the disabled experience, and obscures the difficulties that disabled people experience as a result of an ableist society (Begon, 2023; Grue, 2015b).

moving and generative conversations about mad and disabled experiences of love, grief, joy, hate, and pain felt all at once comes from an interview with *Falak*, a queer and disability activist. They spoke at length about learning from queer activism and trying to find a framework that would encapsulate their disabled experience of joy and grief and pain at the same time. Speaking about their efforts to try to express the joyous and also the non-joyous parts of their experience, they turn to madness:

I think madness gives you scope for joy and that does not mean it is only joyous. I think that it forces you to confront it, you know. The fact that there is this disability, my brain can do some pretty fucking incredible things and just, it always has. And it does some really stupid things and it always has. (*Falak*)

This is an excerpt from a much longer conversation between *Falak* and myself, as I worked through my own thoughts with them. Like my interlocutors, I too, am constantly in a struggle to understand how to bring together joy, grief, rage, love, hate that come from and through my disabled self. What existing frameworks might allow for that? What other aspects of my being might I draw upon? Can there be a psychosocial disability that could encompass all this messiness? As *Falak* and I talked, we drew on our experiences of queerness and disability, trying to articulate the experience of crip pain and crip grief, where they might emerge from, and what we can generate through them.

There's caste problems in queerness. There's class problems in queerness...there is of course body problems in queerness, but falling into queerness was like falling in love. On some level it was, it was that confrontational. It was all of that drama that comes with it. But falling into disability was falling into hate and why? (*Falak*)

During the interview itself, I wrote down the phrase “falling into hate”, underlining it several times, almost breaking through the paper as I did. I have never said it as such, but it rang true for me, and I know from my work and friendships, for so many other folks. Was it because psychosocial disability itself came with so much day-to-day pain? But then did it not also come with the joy? Whether it was the joy of crip/disabled communities or what *Falak* called the “joy in madness...whether it was an irrational slash biomedical hysterical kind of joy” *Falak* provides no answers but deeply desires “the space for hating the body”.

I want that ability to have, just to say it, to process it, to be pissed off with it. Where is the space for me to, you know, and I'm not saying this kind of self-loathing that comes

from constantly living in a world, I'm just saying some days I hate my mind. And I'm okay with that. (*Falak*)

J. Logan Smilges (2023) argues that negativity i.e., frustration, sadness, anger, grief, can be a powerful tool for liberation. They are authentic responses to an ableist world and by allowing for these responses, we can truly engage with the oppressive structures disabled folks are forced to navigate. More than just an acknowledgment of these parts of our being, both Smilges (2023) and *Falak* understand negativity as a generative location from where we can understand and live our full crip lives. However, while Smilges (2023) largely discusses negativity separate from joy, for *Falak*, it is important to find a framework and setting where we do not reinforce artificial boundaries between positive and negative emotions. For them, joy and grief/pain cannot be separated from each other and more than existing together, they are deeply interdependent.

But are we to seriously say that where there is grief there is no love. I mean, that is where it comes from, right? Those are the roots. You cannot have one without the other.  
(*Falak*)

I think what *Falak* desires, and what so many others in this research, and in my life, desire is a politics that does not shy away from the messiness of being mad/disabled/crip, a politics that holds hate and suffering as well as love and joy. For *Falak*, it is possible that madness could provide an entry point into such a politics because “there’s freedom [that comes with] madness because it does not play by your rules at all”.

The disability politics that my interlocutors dream of and enact are not linear or straightforward, rather they are subversively messy. They reject the linear paths of medicalisation but also the linear paths of mainstream psychosocial disability and in doing so, open new avenues for understanding and doing psychosocial disability. Like for Kaba (2018), their hope for a crip utopia “doesn’t preclude feeling sadness or frustration or anger or any other emotion that makes total sense” (p. 14).

In conclusion, my interlocutor’s insistence on survival as complete and complex people in the face of a hostile world which at best erases that complexity and at worst erases their existence is a collective political act. Their version of the process of building crip utopias does not draw distinctions between grief and joy, between love and hate, or between loud and spectacular resistance and the quiet everyday resistance. It holds it all.



## **7.4 Re-framing bodily autonomy, care, and access through everyday activism**

This section continues to focus on the everyday actions of my interlocutors. I ask and answer questions which include: in what ways are my interlocutors attempting to, and sometimes succeeding in, living lives and forming communities in the shape of their dreams? How do they (re)interpret disability concepts of autonomy, care, and access through their everyday interactions? How do these seemingly ‘small’ actions relate to our collective political dreams and struggles? I answer these questions by examining in depth how participants detach concepts of bodily autonomy, care and healing, and accommodations and access, from their institutional meanings. Rather through their everyday activism they re-frame them in the image of their utopian dreams. I argue that “utopia exists in the quotidian”, i.e., the everyday is a key arena of activist action and prefigurative politics (Muñoz, 2019, p. 9). Further, the everyday actions taken towards our political utopian dreams are not separate from action at institutional and/or structural levels, but rather they are interdependent.

In the first sub-section, I look at how my interlocutors use concepts from queer movements to think differently about pleasure and bodily autonomy. In the second sub-section, I focus on the creation of small webs of support and friendship and how my interlocutors move beyond recovery narratives and re-frame care as communal healing. Finally, I highlight how my interlocutors detach reasonable accommodations from their institutional and legal meanings and engage with each other through a lens of collective access. They take these actions in the face of possible or even inevitable failure, positioning crip utopias built on care and access as a project in the making.

### **7.4.1 The mad disabled body: more than a site of violence and pain**

The bodymind as a site of sex and pleasure came up more often than I had anticipated in the interviews. There is little to no mention of sexuality and pleasure in the psychosocial disability literature. I attribute the presence of this conversation in my interviews to the fact that many of my participants work and live at the intersection of queerness and disability. The centring of multiply marginalised folks’ work, in this case queer disabled folks, opens new ways of thinking about disability. *Sanya* said as much explicitly, citing the example of queer activism against the ban on sex toys, which for them is very much an issue of disability as well. They went on to say that within the mainstream disability movement, the body, its sexuality and autonomy was only discussed through “lens of violence and harm”, i.e., the body as a site of sexual violence, or as a site of violation of autonomy. They go on highlight that the disability movement could learn a lot

from the queer movement, in terms of centring or at least including pleasure and consent as part of discussions of disabled bodies.

Even when one [within the mainstream disability movement] was thinking about issues with the body, sexuality, autonomy [it] was very much from this lens of violence and harm, right? And there was very little discussion around issues of consent, about bodily autonomy, about pleasure. So really like really kind of trying to bring in those ways of thinking about sexuality. (*Sanya*)

Through the work of my interlocutors, I can clearly see the connections between so many issues—queerness, disability, marginalised bodies. *Falak* talked about the overlaps between “kink spaces” and “disability and neurodivergence” as a way through which we can re-frame issues of “bodily integrity and consent for disabled people”. *Abhishek Anicca*, a physically disabled activist, talks about “heteronormative notions” of love and sex which do not align with their particular disabled bodymind and spoke about finding place for their body and desire in “fetish”, “wildness” and “other forms of pleasure”. Both use language they have learned in queer settings to talk about disabled sexuality and pleasure. In Chapter IV, I quoted *Ambika* and others when they talked about the body being a site of mediation between the self and society. *Ambika* at another point in their interview talked about how desire, felt and expressed through the body, is not just a personal matter, but intertwined with politics of caste and queerness.

Who we fuck, who we like, who we do not fuck, who we find desirable is also very intertwined with structures of caste, this, that. Or also sometimes what is forbidden, you know?... But just the idea of either trying to break away from being a desirable body or wanting to be—or admitting to wanting to be a desirable body, you know? Either of the two. But just being there so much... discontent and heartbreak in that. (*Ambika*)

They discuss desire and bodies in relation to their experience of eating distress<sup>68</sup>, (i.e., “admitting to wanting to be a desirable body” or as “trying to break away from being a desirable body”) and embed that discussion within structures which create a hierarchy of bodies. In doing so, they are highlighting, for me, the generative potential of intersectionality through which new ways to understand, express, and mobilise crip emotions are created.

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<sup>68</sup> The term ‘eating distress’ (instead of eating disorders or more specific diagnoses) is used by some survivor activists and scholars to move away from medicalisation, include people who struggle with eating distress but do not fit the diagnostic criteria, and to emphasise the emotional, political, social, and economic factors underlying ‘disordered eating’. For more on this, refer to Louise Pembroke’s book called *Eating Distress* (Pembroke, 1992).

Discussing desire, pleasure, and sex as a part of a psychosocial disability life in the context of the invisibilisation of these issues within mainstream psychosocial disability movement, and a broader society which is reticent to discuss sexual pleasure, is a political act (Anicca, 2023). Understanding and enacting the disabled body, like the queer body, as a site of pleasure and desire is to challenge the dominance of normative sexualities and normative ideas of bodies.

#### **7.4.2 Care and healing in the everyday**

I want us to keep dreaming and experimenting with all these big, ambitious ways we dream care for each other into being. (Piepzna-Samarasinha, 2018, p. 65)

My interlocutors, through privileging friendships and community as sites of providing and receiving care in service of a communal healing project, are re-writing what psychosocial disability care is and can be.

First, alongside large scale and funded NGO-led projects they worked on, *Sanya* described creating “really small” settings for people and communities to gather. They worked on providing places for “communities of women with disabilities who are in sex work” or “people who identify as trans and disabled or Dalit and disabled” to just come together and talk (*Sanya*). The communities they mentioned are those who are either not included within most mainstream convenings or are included as tokens and face violence within such convenings. Another interlocutor, *RP*, who runs a psychosocial disability group which supports deinstitutionalised people in the community, has incorporated peer support, friendship, and gossiping in their work. They warmly describe the importance of informal or short conversations in building a sense of belonging and community.

So, there are a lot of these gossiping...sometimes there have been our peers who are about forty plus, and they would tell these women [in the community] that they want to get married, and they want to find a good guy and all. So, all these chats would happen during the gossiping session where all the neighbourhood women are sitting and talking to each other. These kind of nuances, we build into the project. (*RP*)

There was an elderly person, [who] had a very terrible life...And so we became very close friends...He was going about his life. There were ups and downs, obviously, which we navigated like friends, you know. And what sustained him was a lot of reading books, a lot of intelligent conversations, of course, friendly conversations, hanging out with friends. (*RP*)

Within the context of the NGO world which demands scale-able, tangible, and marketable projects, fostering “moments of counter-hegemonic warmth, valuing smallness, proximity, relationships, connection, care, and affection” is subversive and an act of defiance (Osborne, 2018, p. 151). For my interlocutors, these acts are not tokenistic ideas of being together and being in friendship nor are they a co-option of community relationships, they are explicitly political.

Second, and through the work described above, *RP* and their organisation are changing how ‘care’ is done, and in doing so they are changing what ‘care’ is. Adopting the ideas of a peer support group, they are re-positioning people with psychosocial disabilities as those who can provide care, not simply as passive recipients of care. They explicitly detach themselves from the language of recovery, which for them is an individual project achieved through the provision of care by a professional. Instead, they use the language of healing, which reflects a “deeper thing” and emphasise that theirs is a project of communal healing, one that requires the everyday acts of care and togetherness that they describe above.

Your environment has to heal. It’s a connection between you and everything else, you know? So, everything heals through you also. And it is a process. All of us are healing. It’s a process...they’re layers of it...It’s a continuous process of healing. Yeah? It’s not like one stop recovery. (*RP*)

Like ‘existence as resistance’, healing too, for most of my interlocutors is a political project. *Bhanu Priya*, a disabled DBA activist, is clear that ‘healing’ for them is beyond individual or even social healing. Rather, it is a collective intergenerational political project, connected inherently to economic justice and anti-caste politics. When referring to the intergenerational trauma of casteist violence, which then requires intergenerational work to heal from, they say:

I don’t think for our communities, healing is something of a possibility unless social mobility is focused on. So healing is more of a generational project than a one generation one [or] an individual one. (*Bhanu Priya*)

Caring for each other within this project of communal healing through small and everyday actions is often not recognised as a form of activism within the mainstream (Piepzna-Samarasinha, 2018). Piepzna-Samarasinha (2018) in her book on disability justice and care work describes care collectives as both a practical need for disabled people as well as a “site of community and political organising” (p. 43). She goes on to say that within this framework, care “is drastically different from most ways care is thought of in the world, as an isolated,

begrudgingly done task that is never a site of pleasure, joy, or community building” (Piepzn-Samarasinha, 2018, p. 44). For my interlocutors, care is multi-directional and collective, it is both a necessity and a joy, it is everyday living and a political project.

### 7.4.3 *Unreasonable accommodations*

Similar to re-framing care, interlocutors through their everyday actions detach ‘reasonable accommodations’ from their institutionalised meaning. Under the social model of disability and the ensuing jurisprudence, the reasonable accommodations necessary to create a disability-accessible world are narrowly imagined. Furthermore, what constitutes ‘reasonable’ is often left open to interpretation. Through a combination of their utopian dreams and their continual everyday practice of collective access, my interlocutors are re-imagining what accommodations and access mean.

In conversations with my interlocutors, they often repeated how reasonable accommodations are unable to provide them with the access they need. Somewhat tongue-in-check and highlighting the irony of the use of the very loaded word ‘reasonable’ in relation to those who are deemed to lack it, I suggest that what my interlocutors are dreaming up are *unreasonable* accommodations. For me, these are the adaptations which, in the words of *Neba*, change “the nature of the world”. In that interview, and at the end of my interview with *Naina*, we joked/complained about the travails of trying to navigate the ever-increasing demands of work under capitalism.

**Akriti:** And I’m like, “I just need capitalism to end, I need capitalism to end”

**Naina:** Yeah. [chuckles] No. Yeah, that would not be a reasonable accommodation under the CRPD. That’s progressive realisation though, so yeah. You’re getting somewhere.

My interlocutors hold on to their dreams of an accessible world without oppressive restrictive systems such as capitalism and at the same time acknowledge that the everyday work of inclusion is often not smooth, and access needs come into friction with each other. Access for them, is created collectively and in community with each other. *Sanya* described the everyday work of accommodating the needs of mad and disabled folks as “a whole other way of understanding”. For them, it can “appear as basic work” which is “fundamental to ensuring how you are creating some sort of shared space”. Other participants mention the use of quiet rooms/places, building contingencies to enable flexibility into deadlines, encouraging people to lie down if they need to, amongst others. Beyond these tangible and identifiable actions, they describe creating settings

where they can experiment with what works and what doesn't and can have honest conversations with people about their disabled selves and their needs.

And [redacted], who would have moments with her where she's in her high energy phase. And I have to tell her "[redacted] shut up and get the fuck out of my space" because you are high energy right now. I can't deal with you because I'm trying to do a training. And you want to climb the wall, so please climb the wall. Just don't kill yourself in the process... I've been very lucky the people I've met [who] are really interesting [and] just made me completely at ease. Like, so with Nidhi [a blind activist], I remember once, sitting with her and she was saying, "How are you doing?" And I said, "God, you know, today's one of those, those really fucked up days. I'm dressed badly, I'm feeling irritated." And she said, "Aren't you lucky I can't see you." (*Deepu*)

The quote above, for me, is a great example of crip communities and collectives. It describes an instance of access friction, i.e., when two disabled persons' access needs are at odds with each other (Mingus, 2011). It describes how these frictions can be mediated with honesty and transparency about what each person needs, and how that work is done through friendships and relationships with people who can put us at ease. It is also resonant of Mingus' (2011) concept of access intimacy which captures the understanding between disabled folks about their access needs as a type of intimacy that builds within and from a collective crip understanding of the world. Finally, by recalling that last anecdote, *Deepu* is subverting the usual tropes of disability. In this case, one person's blindness provides the comfort and ease for the other person to be present in their "badly dressed" form on their "fucked-up day". There is humour, care, and intimacy in that anecdote, and it is both hilarious and profound.

Finally, while they aspire to continually work towards their dreams, *Raya* reminds me that everyday activism also means a continual vigilance against, and a fear of, complacency. Activism of this sort, for them, is not a given, but rather something they actively decide to do with the knowledge of potential failure.

And I think the fear is what if one day when we get old, we also get, "Okay, we can't do jack shit about [everyday injustice], so might as well just be okay with it". I think I'm carrying that fear, okay? You know, what happens when I grow old and I'm like, 'Okay. *Koshish kar li, nahin hua* [we tried, but we couldn't succeed] so, let's just sit back, because we can't do anything about this. I think that's the most scary thing for me. (*Raya*)

However, *Neha* provides a different way of looking at failure by explicitly acknowledging that care and access are not always possible.

So, I feel like—that the idea that some situations where there isn’t something that we can provide, is something we need to grapple with. We need to accept that there are some things that we cannot protect each other from, right? And that there is a situation where I don’t know what would’ve helped support you better, right? (*Neha*)

While the quote above could be read as despairing and nihilistic, within the context of the entirety of their interview and the whole corpus of interviews, I read it as an admission that even in the face of certain failure i.e., not being able to provide support; we must still try to do so. And that it is the trying, not success, that is the foundation of our utopian dreams. It reminds me of the closing lines of an article where Natalie Osborne (2018) responds to Nēhiyaw philosopher Erica Violet Lee’s (2016, para. 35) view that “to provide care in the wastelands is about gathering enough love to turn devastation into mourning and then, maybe, turn that mourning into hope” by saying “But if not, well, you’ll find me caring in and for wastelands anyway. What else am I going to do?” (p. 152).

Through their rich descriptions of and aspirations for how to re-think pleasure, bodies, care and access within small webs of support, friendship, and camaraderie, my interlocutors are re-shaping how they are ‘done’ on a small everyday scale in the ways we interact with each other. Through this ‘doing’, they are re-formulating what care, healing, access, and accommodations mean in relation to their larger political projects and dreams. In conclusion, my interlocutors through their everyday actions breathe life into their dreams, creating and forming communities based on radical political ideas of resistance, collectivity, care, and access. This is an example of the practice of critical hope. For Kaba (2018), “hope isn’t an emotion, you know? Hope is not optimism. Hope is a discipline... we have to practice it every single day” (p. 14). My interlocutors, through their everyday activism, practice that hope for utopia every day.

### **7.5 The threads that weave the fabric of our dreams**

We, disabled people, we dream a lot. In psych wards, of dead friends, of getting out our parents’ basement apartment, on day 645 of pandemic non-leaving-the-house, of lovers who will be sweet to us in autistic, Deaf, disabled ways... We go to bed every night dreaming of the disability justice future. And we will keep dreaming these wild disability justice dreams, every night and day, until we meet her. We are meeting her right now. (Piepzna-Samarasinha, 2022, p. 47)

Repeatedly and in all interviews, my interlocutors draw hope and strategies from activists, scholars, friends, and ancestors from across time and geography. They do not wholesale or uncritically import their work but rather engage with it, drawing out lessons, hopes, strategies, vibes from them, and using what is relevant to their contexts. They draw from frameworks like transformative justice, abolitionism, and Disability Justice to shape their dreams and their lives. This section highlights the facets of these frameworks which my interlocutors use in their work. Following my interlocutors, I particularly focus on Disability Justice as a framework although many of the principles of Disability Justice are inspired by other forms of justice-based activism. In my interviews and my interlocutors' discussion of the worlds they want to build and are trying to build, I found repeated mentions of several threads: moving beyond disability as *the* issue; the need for centring marginalised folks and redistribution of power and resources; working on multiple levels simultaneously; learning across borders and time; holding contradictions; and embracing the plural. I will take each of these in turn.

My dreams and those of my interlocutors for a just world are founded on the idea that all oppressive structures are interconnected and to dismantle one necessarily means dismantling all. This is a key principle of Disability Justice, a framework that was referred to by many participants (Berne, 2015).

Disability justice is also like raising voice for Palestine. In India how much of a discourse is there for Kashmir... are you ready to talk about blindings in Kashmir, for example? Are you ready to talk about what is happening to Muslims in India? Are you willing to talk about the mass deaths of Dalits which happens while manual scavenging? It's not a disability issue? It is a disability issue. (*Abhishek Anicca*)

There is so much in the quote above and beyond the particular examples it raises. *Abhishek Anicca* is referring to transnational solidarity, to colonialism and occupation, to fascism and both its slow and spectacular violence, to age-old systems of oppression like casteism, to worker exploitation. For him, and for disability justice activists, disability is about everything, all at once. Implied in the quote is the sentiment, sometimes stated explicitly, that in India, there is no disability justice. However, my interlocutors are thinking together about the ways disability justice would/could be done in India, their utopian dreams and their analysis of the present are aligned with Disability Justice frameworks, they are localising knowledges and practices from across time and geography. It is not a coincidence that one of the first books on disability justice included in its title the phrase '*Dreaming Disability Justice*' (Piepzna-Samarasinha, 2018, emphasis



added). For me, the work of dreaming just worlds and enacting those dreams in the everyday is the work of disability justice and of that there are many examples.

My interlocutors are constantly and actively working towards centring issues and experiences of the most marginalised. *Falak* talks about redistribution within the context of the mainstream psychosocial disability movement. She asks of herself, and others:

The question is always why [are you doing this]? Are you actively redistributing a resource? Whether it is the resource of space, whether it is the resource of knowledge. Like knowledge, money, and by redistributing resource of money, knowledge. I think that is effective work. (*Falak*)

My participants work simultaneously across many axes which can address both material injustices and epistemological ones. *Neha* talks about the importance of doing work that is “focussed on education, employment, etc” and “more emotional landscape work” “together and not in isolation of each other”. They talk about navigating what seems like opposites: “grieving and joy”; “our aspirations and having to do some stuff in reality”. The sections above and chapters preceding this one have shown that these exist together, and people navigate that messiness by sometimes choosing one to foreground depending on particular context, but always with the knowledge that the two are not mutually exclusive.

I don’t know how to choose between these two, you know? And I think that people are making the choice, right? Like between this and this...Like even with me choosing between grieving and joy, right? Like, this week is not the week for joy. It’s been the week for grief, you know? So, then I grieve, and hopefully next week I will find some joys [chuckles]. (*Neha*)

The dreams and lives of my interlocutors include worlds inhabited by people, texts, and ideas separated from them by time and geography as well as their immediate everyday lives and context of their activism. By particularising what they learn from the former and adapting it to their local realities, they bring them together and create new avenues for activism and generate new worlds. They reflect on histories of resistance, drawing hope that there has always been resistance. They learn from these histories, people, and texts and localise and particularise their lessons within the context of colonial rule in South Asia, the Partition, and the occupation of Kashmir.

Hard things happen, bad things happen, in all generations. And I say that as a student of history, right? Like, it’s not as if what we’re facing has not happened before. As a

country, as a subcontinent we came out of colonial rule, and we did a lot of work like setting up parallel governments, setting up parallel universities, education systems, healthcare systems. So, it's not as if it's not possible to resist. (*Raya*)

Sharing stories that elders share with their young ones, and it's shared through being together, it's shared orally, it's passed down from generation to generation. I think that would look like the lived experience for me in my culture. And it's not necessarily written in a way to explain that these kinds of things happen, but it's spoken about that there's healing and there's resilience in the experience. (*SL*)

In the quotes above, I find reflections of crip theory, indigenous activism, and anti-colonial struggles which emphasise the need to honour our ancestors and those who came before us, to learn from them, and draw our hope and dreams from their struggles.

Finally, my interlocutors hold and work towards what Rosemarie Garland-Thomson (2011) called for from feminist disability studies—a “methodology that tolerates internal conflict and contradiction” and “what has been thought of as incoherence” (p. 13). *Madhu*, in the context of talking about navigating the differences in the many approaches to madness and mental distress, states:

I'm willing to have those conflicting ideas in my head. And it doesn't kind of compel me to have one answer and strive for it, because I think as we mature and as we evolve, we should be able to hold more and more ambivalence. (*Madhu*)

I want to reproduce a rather long excerpt from one of my interviews as an encapsulation of what it means to think from a place of the uncomprehensive and the partial:

Disability is one thing, and I have to use it quite often. And I have to say disabled person. Then I have to talk about identity. The way I bring in disability now for a lot of people as I start talking about the distinction between person with disability and disabled person and where you need to operationalize those two. Because one of it is very much policy language...but the other one is indicating an identity politics.

But, you know, crip is powerful. And it always has been crip as a lens, as a feeling that made so much sense. Crip was the thing in my spine that made the difference. But the question I suppose I need to ask myself also is can you crip everything? Is that possible? Is there a way to take crip out of the language we know it from and say that this is one of the ways that we can sort of 'disable' spaces? Because again, crip is identity...I don't want to say theoretically in a way to distinguish the theoretical and the physical. I'm just saying

crip gave me language. And crip gave me a very, very different kind of language. And I would not be here were I not able to access it. However, the distillation of that, like how do I enact my politics if crip is my politics?... What does a Crip movement look like? What does a Crip civil rights movement look like? It's worth asking. I am constantly asking myself; I'm trying to figure out a number of things...*I'm so far from fully formed on this. I don't think I ever will be.*

...Crip is also rooted in queer movements...Are we doing disability only as queer? If we're doing disability only as queer, why do queer spaces have such an issue with disability. If we are doing crip as queer, then what are we doing about disability? And if we're doing crip as disability, then what the fuck are we doing about legislation and then policy?

Disability Justice is one of the spaces I think that things begin to operationalise. And I like that because disability justice is something that you can put forward at a conference, which you can use to challenge people, which is where you use to fight funders and corporations and the government. And it makes sense...It's talking about centering, lived experience. It's talking about sort of the redistribution of resources. It's doing all of that. But then is crip an identity exercise, which is fine, which is okay. But are we going to leave it at an identity exercise? Like what does that mean? Is crip disabled? I'm not sure.  
(*Falak*)

I love this passage so much and for so many reasons. It talks about navigating policy vs identity. It talks about the connections between theory and what we feel viscerally. It talks about how theory and movement connect or don't connect. It talks about where our understandings are rooted. How different ideas, concepts, theories, and movements might be connected. How those connections can be operationalised. It connects experience, identity, theory, structures, history together and it provides no answers. And despite providing no complete or comprehensive answers and resolutions, it is generative and rich.

Part of what I wanted to do in this project was to connect the knowledges generated in/from different locations. Scholar activists talk about the need for connecting activism and scholarship. Disability Justice talks about the need to honour our ancestors. Activists and academics alike talk about the importance of building trans-national solidarities. Many of my participants are doing just that in their everyday lives. My participants speak about activism, academia, and experience in the same breath. They talk about crip time and crip theory, organising collectives and reasonable accommodations, and pain and body, moving seamlessly between these realms

critiqued for being distant from each other. And in doing so, they are actively doing the work so many of us are trying to do.

They are working in the plural, seeking not a singular framework, knowledge, or activism. Rather my interlocutors seek multiple frameworks and knowledges from and of a multitude of worlds, and activisms. *Falak* explicitly highlights this plurality in their ideas of where we go from here:

I don't want a singular space that's like talking about singular disability. It's like talking about singular queerness. You're not going to get class, you're not going to get caste, you're not going to get region, you're not going to get language...you're not going to get religion, you're not going to get communal violence. It's not going to happen. It's not going to happen. And I don't want it to. And so, the question is then how do we navigate *spaces* plural? (*Falak*)

## **7.6 Discussion and conclusion**

My realisation was that there is no I and them, and there is only us, you know, together trying to navigate this complex world and all of that. (*RP*)

The collective generation of new knowledges and worlds which my interlocutors bring into being through their everyday activism might be a mechanism for survival borne out of a hostile world, but it goes beyond survival. Rather, crip utopias enable all of us to imagine new ways of doing activism of all sorts. My interlocutors bring their dreams of a just world into being through their experiments with different ways of coming together, i.e., they form collectives; they practice their politics in their everyday engagements with each other and with the world; they acknowledge and try to navigate all the different and difficult emotional aspects of being disabled and engaging in disability politics; and they embrace a politics of disability that is both trans-national and localised, that is not comprehensive because it can never be, and that centres a plurality of actions, thoughts, knowledges, stories, strategies, and practices. They interrupt, disrupt, and dismantle the imagined boundaries between success and failure, between the embodied and the structural, between joy and negativity, between love and pain, between hope and despair, and between the present and the future. They know and enact the knowledge that our liberation is linked to the liberation of all people, and our actions must reflect that. They do this by dreaming big and doing small.

Dreaming and working collectively is both an end and a means within crip utopias. Ableism and all its hostilities, along with the increasing neoliberalisation of our world, often keeps us isolated from each other. Coming together as mad disabled people to talk about our hopes, to hang out

and eat or laugh or cry or sleep, to care for each other, and to work and take collective action is often a world we dream of while we attempt to cope with our jobs, our tired and exhausted bodyminds, our inaccessible public transport systems, and the many other things that keep us separate. Coming together as mad disabled people is also how we generate knowledge and come up with new ideas. Collectivity in this way is central to ‘doing’ psychosocial disability.

Equally, my interlocutors do not romanticise or paper over the difficulties of forming a collective or being in collectivity with each other. There is always the potential for perpetuating oppressions and doing harm to each other; there are frictions in what we need from each other; the things that grieve us, cause us pain, and give us joy are different as are our expressions of them. Working on and through these difficulties and challenges is part of the work my interlocutors do collectively. Earlier in the chapter, I highlighted their hope for a movement populated by multiple small collectives working together towards a common goal of justice “where we’re okay to step down the moment we think that ‘Okay, this is getting too much and somebody else can step in’”. This quote, for me, reflects the incredible emotional toll of any type of activism, especially within the context of psychosocial disabilities. Yes, it is rewarding and there is joy and smiles and friendship, but there is also fear and exhaustion and distress and all of it is part of ‘doing’ psychosocial disability.

My interlocutors’ dreams and practices hold many ideas at the same time. For them, disability is about everything, all at once. It is a matter of dreams and of reality. It is a matter of grief and pain and of pleasure and joy. It is a matter of caste justice, of queer futures, of anti-colonial struggles, of no more military occupations, and of an end to fascism. It is both attempting to work within the world as it is, with the material realities of life within capitalist and fascist societies and refusing to accept that this is all the world is by dreaming and ‘doing’ radical dreams. They are living Disability Justice despite some of their statements that it is not in practice within disability activism in India. Piepzna-Samarasinha (2018) wrote that “...the making of disability justice lives in the realm of thinking and talking and knowledge making, in art and sky. But it also lives in...how to learn to care for each other when everyone is sick, tired, crazy, and brilliant. And neither is possible without the other” (p. 24). And that is everywhere in my participants’ world.

My interlocutors belong to and come from many different worlds. Some of them live and work in close proximity with each other, i.e., they are close friends, comrades, colleagues; some are not from a crip world, i.e., they locate their collective action in queer, Dalit, and other locations; some are separated by time and geography. Their ideas and work belong to a much larger project

of collective action spanning centuries and the world over. They move between these worlds referring to scholars, concepts, and theoretical framings alongside practical and everyday strategies of organising seamlessly. My interlocutors borrow concepts, ideas, and theories from across time and geography and contextualise and localise them. They experiment with different ways of ‘doing’ our wild dreams, with full knowledge that everything they do is a work-in-progress.

In their practice of prefigurative politics, and living their dreams, they are bringing the future or the potential future into the here and now. This by itself is a radical and generative rejection of the borders of place and time. Crip utopias for them are inherently against dichotomies—our bodies fail us and we fail each other and through that we generate new ways to care; grief and love and hate are not separate, they come from and through each other; we do things in the present because we dream the future and equally we can breathe the future into life because we do our dreams in the present. A mad crip utopia doesn’t hide from or pretend to neatly categorise all the complexity of our lives and our world, it is the practice of living in “the partial, the provisional, and the particular” and embracing the uncomprehensive and the incomprehensible (Garland-Thomson, 2011, p. 40).

I started this section with the quote *dekho, humne dekha hain ek sapna*. It is hard to translate this exactly, but a word for word translation would be—see, I have seen a dream. I was discussing this phrase and this song with a dear friend/comrade, and they pointed out the repetition of the word ‘see’ in the phrase and song. We wondered if the entire phrase is not simply an assertion of “our dreams”. Rather, by putting the word *dekho* i.e., look/see, at the beginning, the phrase is also inviting someone external to your dreams to look at your dreams. It is inviting the world to look at our dreams. And maybe, just maybe, the work of psychosocial disability in this intersectional radical way is “an invitation to dream, an invitation to consider, an invitation to build, to experiment, and to act” for all (Hayes & Kaba, 2023, p. 6).

*Interlude: the view from my desk*





## **VIII. Conclusion(s)**

We must leave evidence. Evidence that we were here, that we existed, that we survived and loved and cared. Evidence of the wholeness we never felt and the immense sense of fullness we gave to each other. Evidence of who we were, who we thought we were, who we never should have been. Evidence for each other that there are other ways to live—past survival past isolation. (Mingus, n.d.)

### **8.1 How I got here?**

Mia Mingus in the quote above encapsulates what I wanted to do at the outset of this project. I first came across the term psychosocial disability in 2016. In the ensuing years I came to understand one framework of psychosocial disability—the one that emerged in opposition to the colonality of user/survivor movements and through an identification with the social model of disability. When I started this project, I knew or at least had a hunch, developed through friendships and engagements with people who were less visible on international platforms, that there were other understandings of psychosocial disability.

I set out, in this project, to take a snapshot of a moment in time when a plurality of psychosocial disability understandings existed and flourished, before they got co-opted and incorporated within mainstream psychosocial disability. In other words, I wanted to add to the evidence that my interlocutors were leaving. In many ways, that is where I have ended up at the conclusion of this thesis—leaving evidence.

In other ways, I am a long way from where I started. I came to realise the depth and breadth of work that was flourishing outside the mainstream movement. My project changed from an urgent desire underpinned by despair to capture something before it was lost to a more hopeful knowledge that psychosocial disability activism, including this thesis, is a small part of a much broader collective project of dreaming and doing justice. The project is about psychosocial disability, but it is equally about how people navigate a deeply hostile world, how they resist and challenge the multiple layers of marginalisation and oppression, how they co-exist between needing institutions and knowing that those institutions can and do harm, and how we understand, process, and collectively mobilise our distress. These are questions I have asked of myself long before I had the language to ask them in this way and these are questions that will live on long after the phrase ‘psychosocial disability’ falls into disuse.

Through an analysis of psychosocial disability activism in India, I argued that psychosocial disability at the margins is an ongoing practice of refusing binaries and holding multitudes; of



constantly negotiating the compromises and complicities that are presented by hostile worlds and imperfect ‘solutions’; of eschewing neat resolutions and singular principles and stories; and of creating worlds and knowledges through messiness and uncertainty. I argued that these practices emerge through intersectional engagement with disability and resonate with scholarship and activism of all sorts.

## **8.2 What did I find? Summaries of findings**

I set out initially to interview people both at the margins of and within the mainstream psychosocial disability movement. I wanted to start with those at the margins, whose work I was least familiar with for two reasons. First, I knew that early interviews would influence the questions I would ask in later ones, and I wanted to ensure that my questions remain grounded in intersectional activism. Second, I was most familiar with the mainstream psychosocial disability activism (through what I read and my own relatively privileged life experiences) and needed to disrupt and unsettle my own assumptions about understandings of psychosocial disability. Although I did interview some people who could be described as senior activists, i.e., who have been in/around psychosocial disability activism for decades and hold power within them, by and large I did not interview people who are perceived to be at the centre of the mainstream psychosocial disability movement. Even those who can be described as senior activists were either ousted from the mainstream movement or were disillusioned with it.

When I first sat with the entire corpus of these interviews, I was overwhelmed with the task of trying to make sense of them all, to stitch together these seemingly disparate and contradictory accounts into a comprehensible and comprehensive framework of psychosocial disability, a story of psychosocial disability which stood outside of and/or challenged the mainstream narrative. It would be nice to be able to say that I overcame that paralysis and subsequently produced bounded answers. However, in reality, I found myself in the place of overwhelm again and again and yet again, right up to this very moment of writing this conclusion. Academia expects a comprehensive and confident telling of answers but over time, influenced by scholar-activists from across the disciplines of queer theory, decolonial and postcolonial studies, crip and feminist theory, I learned to shed or at least ignore the weight of that expectation. I set out to understand what was going on outside of the singular psychosocial disability understanding and to truly do that, I had to internalise what I knew but did not always centre—one cannot replace a universalist narrative with another universalist narrative. I had to embrace what my interlocutors create in their daily life—*stories*, in the plural, of psychosocial disability.

Literature on disability and activism more broadly is rife with debates and critiques about how to bring together scholarship and action, the pros and cons of engaging with and organising through NGOs or through informal collectives, how to navigate the difficulties and complicities of engaging with psychiatry and legislative reform, how to ‘do’ intersectionality in everyday practice of activism. Taking a perspective of epistemic justice, I interviewed psychosocial disability activists in India, foregrounding those intersectionally marginalised, to learn about contemporary disability activist practices and knowledge. In their practice grounded in lived experience, and informed by political awareness, these activists traverse, juxtapose, engage, and work with contradictory forces side by side, day in and day out, and try to find a liveable balance. I argue that this *is* the work of disability justice, and it is alive and well and thriving in practice. We have seen this across the chapters, through various themes and contexts.

In my first empirical chapter, Chapter IV, I set out to answer how psychosocial disability is constituted and understood. In 1982, Lorde (1982) in a speech said “if I didn’t define myself for myself, I would be crunched into other people’s fantasies for me and eaten alive” (para. 12). I argued that through a process of disidentification, my interlocutors use aspects of the different models of madness and disability and reformulate them into an understanding of psychosocial disability as a radical lens which can then hold the different and seemingly contradictory facets—structural, visceral and embodied, emotional—of their experiences and of the world.

People who experience distress and/or unusual experiences have been subjected to the imaginations of many frameworks and institutions, the psychiatric patient and the disabled person being the most relevant to my thesis. Psychiatry would have our lives and experiences crunched into diagnostic categories, to be cured or managed but never acknowledged as anything but pathological. On the other hand, and in opposition to the patienthood imposed upon us, disability as espoused by the mainstream psychosocial disability movement would have us believe that if only ableist social barriers were removed, we would be free of our oppression. My interlocutors living and working as they do at the intersections of many interlocking structures of marginalisation find both lacking. Psychiatry is dehumanising but also necessary to access resources, and disability is useful to locate a problem outside of the self but also incomplete and unable to capture their experiences. In community with each other, my interlocutors attempt to find a way to explicate the structural causes of impairment and distress as well as its embodied and felt experience. They do not “wait around for the ‘right’ or ‘correct’ theory—one that solves all the challenges they face—before they act to defend or advance their collective interests.” (Anderson et al., 2015, p. 289). Rather, they bring together the useful facets of psychiatry and diagnoses, a psychosocial disability identity and category, the social model of disability, crip

theory, debility, and neurodivergence, and create a new and dynamic understanding of psychosocial disability as a lens which enables them to not only hold different aspects of their experience together but also lends itself to be mobilised to address disability as an intersectional issue.

In Chapter V, I asked and answered how psychosocial disability is ‘done’ with respect to the major institutions and discourses which govern it, i.e., psychiatry and human rights. I argued that my interlocutors ‘do’ and mobilise psychosocial disability intersectionally by incorporating elements of radical and non-reformist reform to navigate psychiatry and human rights, framing them both as poison and medicine, eschewing ideological purity, and embracing strategic engagements with these systems.

The mainstream psychosocial disability framework and activism in India has taken a position of complete disengagement with psychiatry and an uncritical acceptance of disability rights as liberatory. However, as my interlocutors point out, both assume that the subject of these positions can choose to engage or not engage with psychiatry and can rely on the state to redress rights violations, i.e., the unmarked subject of these debates and positions is a person privileged within class, caste, gender, religious, and sexuality norms. In a different context of whiteness and disability studies, Bell (2006) said that disability studies “treats people of color as if they were white people; as if there are no critical exigencies involved in being people of colour that might necessitate these individuals understanding and negotiating disability in a different way” (p. 282). My interlocutors parallel Bell’s people of colour; they belong to communities and groups which are multiply marginalised. They cannot disengage with psychiatry completely because they need to access it and the alternatives offered by the movement (community and spirituality) are sites of violence for them. For them, disability rights are useful in some circumstances but their experiences, especially in the context of a fascist state, make them wary of turning to the state for protection when it itself is often the source of violence and distress.

I find that they live and work in the often-uncomfortable liminality “between the radical potential of a revolution yet to come and the material benefits of a life currently existing” (Sandoval, 2017, p. 82). They do this by heterogenising the institutions and their subjects, i.e., contextualising their action depending who is engaging with which parts of mental health and state infrastructure; they pose a challenge to the absolutist and ideologically pure demands of the mainstream movement by marking the unmarked subject of the movement’s actions; and they undertake work that espouses values of radical and non-reformist reform, i.e., they are careful or

at least acknowledge that their engagement with systems must not reinforce their ability to do harm.

In Chapter VI, I shifted my focus to understand how the psychosocial disability movement itself is organised. I found that the logics of neoliberalism and the forces of fascism work in concert to create a reward and punishment system within it. This system works to exclude marginalised and targeted communities and people as well as politicised readings of disability and madness from mainstream psychosocial disability.

My interlocutors live and work within a context of marginalisation within society but equally they are faced with it within ‘activist’ and ‘movement’ settings. My interlocutors’ understanding of the concepts ‘activism/activist’ and ‘movement’ emerges from the stark schism between what they imagine these concepts to be—grounded in the grassroots, espousing a radical identity politics, a mass swell working towards a common goal, led by persons who put the movement and its goals before their self-interest and self-promotion—and the reality of psychosocial disability movements which are populated by people and organisations untethered from the grassroots, unable to hold or navigate differences, and centred around a few leaders who hold and exercise power to promote their own visibility.

The psychosocial disability movement itself is shaped by the superstructures which govern it—NGOs which internalise the mechanisms of neoliberalism and capitalism, a transnationally imposed ecosystem and its coloniality, the demands of an international funding system which relies on and rewards short term projects led by star ‘activists’. Added to this unholy mix are the forces of Hindu nationalist fascism—the criminalisation of dissent, restrictions on foreign funding, and normalisation of religious persecution, hateful norms, and violent actions within broader society including the psychosocial disability movement. The mobilisation of psychosocial disability as a lens seeks to address issues like the occupation of Kashmir, Islamophobia, militarisation in the Northeast, Brahminical patriarchy, and fascism, in this violent and exclusionary context. Foregrounding people who live and work in these targeted and marginalised settings is made dangerous and difficult by the current shape of the mainstream psychosocial disability movement. Some actors and people give into its demands and replicate oppressive structures within it and others find ways to resist. Despite the complicity of these settings in creating and exacerbating distress and disability and despite my interlocutors’ frustration and disillusionment, they continue to disrupt these depoliticised settings as well as find new settings to enact their political understandings of psychosocial disability.

In the final empirical chapter, Chapter VII, I focussed on the possibilities, futures, and pathways that lie within psychosocial disability activism at the margins and how these are understood and ‘done’. I argued that by dreaming crip utopias and prefigurative politics (doing it in the everyday, individually and collectively), my interlocutors break down the rigid boundaries between the dichotomies of the everyday and the structural, between success and failure, between grief and pain and joy and hope, and between the present and the future. In this way, they expand our imagination of what intersectional understandings of psychosocial disability are and can be.

Despite the constraints and difficulties they face within the mainstream psychosocial disability movement and their ensuing disillusionment, my interlocutors express their hopes and dreams for a justice-based future. They bring together their concerns about casteism, militarisation, capitalism, cisheteronormativity, and a host of other issues in their utopian dreams. Their “imagining of collective subversive futures” are rooted in and ‘done’ through everyday actions of care, collectivity, and access (Sandoval, 2017, p. 68). They experiment with different ways of coming together, forming collectives and friendships. They try and sometimes fail to find room to express care, love, grief, and pain and to create collective access. In the words of Lorde (1982), they “are making the future as well as bonding to survive the enormous pressures of the present, and that is what it means to be a part of history” (para. 39).

Across these chapters, I find that my interlocutors are engaged in a practice of psychosocial disability that emerges from their collective dreams and intersectional analysis of the world. It is rooted in the knowledge that everything is connected and that our liberation is inherently tied to the liberation of all and that there is no ideologically pure or perfect way to action this knowledge. Rather psychosocial disability itself is the practice of continually negotiating contradictions and compromises and tolerating discomfort; and that this type of practice, like everything else, is open to co-option and opportunism, and requires constant vigilance and protection.

Garland-Thomson (2011), writing about how a disability analysis can add to and deepen the traditions of feminist academic activism argues for a “methodology of intellectual tolerance” which can hold and embrace “internal conflict and contradiction” (p. 13). For her, “the disabled body is contradiction, ambiguity, and partiality incarnate” and she argues for a feminism and disability politics which “espouses the partial, the provisional, the particular” (Garland-Thomson, 2011, pp. 40-42). Intersectional engagement with psychosocial disability for my interlocutors is a practice in embracing/working towards the particular, the provisional, the partial, and I would add the plural.

My analysis shows that my interlocutors are inspired by people and ideas across time and geography, but these lessons are always localised and particularised to their context. They move seamlessly between activist and academic knowledges, adapting what they need and what helps them make sense of the worlds they live in. They always present this work as provisional—it is a work in progress, ongoing and evolving, never to be finalised, but always to be worked on and towards. For them, psychosocial disability is about everything all at once, but they do not put forward some comprehensive framework, their understanding and action will always be partial and unfinished. Finally, psychosocial disability as a practice means discarding singular linear stories about our lives and the world, it is both knowledges and activism in the plural. This partial, provisional, particular, plural method of disability politics can be so generative and rich.

### **8.3 Why does it matter? Themes, contributions, and interventions**

I struggle to find that one sentence which encapsulates what I have found out and what it offers to broader scholarship. My primary contribution is a critique and expansion of disability studies and activism, particularly the ways in which models of disability, including the social model of disability and the human rights model of disability, are framed, circulated, and mobilised. For broader scholarship, my key empirical, methodological, and conceptual argument is fundamentally an obvious and well-established one—it is very complicated and very difficult to do intersectional justice-based activism. I showed how and why it is complicated, where difficulties and tensions arise, what pathways might exist to navigate them, and how people continue to work towards their dreams despite the constraints they come up against. Ultimately, what I found, as have many scholar activists, is that navigating the complexity and messiness of such activism (rather than simplifying, decontextualising, or denying it) *is* the work.

#### *Empirical interventions*

Disability studies has largely ignored madness/psychosocial disability as has cross-disability scholarship in India and psychosocial disability literature is either focused on fitting madness into the social model of disability or as is the case in India, centred around a singular story of psychosocial disability identities and categories. These are critical gaps and through my detailed presentation of psychosocial disability activism outside of the mainstream, I make empirical contributions relevant to these and other bodies of literature.

First, psychosocial disability as an identity has an origin story—it is a challenge to the coloniality of psychiatry and the user/survivor movement and is an inherently liberatory identity. I disrupt this singular story. I show that coloniality persists within the concept and framework of

psychosocial disability. Its standing as a category and identity remains bound up within the colonial legislative and medical understandings of disability. Furthermore, I show how global North-based funders and institutions (including the UN) shape the priorities of the movement through transnational flows of capital and organisational and movement structures. In these ways, psychosocial disability in and of itself does not present a challenge to coloniality. Rather it must be 'done' in ways which enable it to adapt to the shifting manifestations of geopolitical power imbalances.

I critique conceptualisations of psychosocial disability as an identity and a category, but in line with my interlocutors, I do not dismiss their utility. In arguing for, and presenting evidence of, psychosocial disability as a lens, I move beyond critique and provide a flexible and adaptable way to understand and 'do' psychosocial disability. Psychosocial disability as a lens moves us beyond who is and isn't psychosocially disabled. Rather it can be employed to understand how marginalising structures are experienced as disabling, to bring disability concepts and activism to non-disability activists, and to 'do' activism which go beyond single-issue organising.

Second, within survivor literature as well as psychosocial disability and cross-disability scholarship, psychosocial disability is bound up in UNCRPD-centric legalistic models and the social model of disability. The former body of literature is somewhat fixated on if/how madness is aligned with social models of disability and whether the UNCRPD is good or bad. The latter is focused on an uncritical and wholesale acceptance of the UNCRPD and the social model of disability as good. I disrupt these binaries of good vs bad and aligned vs unaligned, by presenting evidence of how my interlocutors navigate this debate. By understanding and doing the social model of disability and the UNCRPD as both useful and useless, they change the terms of the debate. The question needs to be, and for my interlocutors is, in which contexts can these models and frameworks be leveraged and for what purpose. For example, my interlocutors recognise the futility of relying on international and national rights to protect those who the state considers undeserving of rights. But equally they will use pathways and opportunities provided by the UNCRPD and national legislation subversively in individual cases, to bring attention to ignored issues like the military occupation of Kashmir, or to highlight the distress of religious minorities under fascism. However, they do this with the knowledge that these models are mere tools and not the end goal.

Third, taking a global South approach, I am aligned with crip theory and critical disability studies in re-introducing the body often neglected in disability literature centred on the social model of disability as well as disrupting the neutrality of impairment under the social and rights models.

Many scholars write provocatively and convincingly about the physical impairments and disability caused by capitalism and colonialism in the global South. My thesis is informed by and resonates with the corpus of scholarship that is concerned with structural violence and disabled bodyminds. None of my interlocutors have faced the spectacular physical violence of fascism in India, i.e., they have not been lynched in the streets for being Muslim or Dalit or blinded by the military in Kashmir or been injured in industrial ‘accidents’, yet they experience a continual atmosphere of fear, grief, and pain caused by the real possibilities of such violence. As one interlocutor stated compellingly, being part of a marginalised group by itself is “enough to be psychosocially disabled” (*Roop*). By delving into the experiences and analysis of interlocutors who face different forms of repressive violence and understand them through a combination of their bodies and minds and explicating how being part of a community marked for potential violence is itself a disabling experience, my thesis is aligned with and add to the empirical scholarship of Southern disability researchers.

Fourth, policy worlds and crip worlds, rights-based activism and justice-based activism, medical intervention and community focus, radical action and realistic concerns live and are done in siloes. They are understood as mutually exclusive and at odds with each other. As activists and scholars, we are instructed to pick one and locate ourselves there. Psychosocial disability literature lives in policy, rights, community, and realistic concerns. Disability justice lives in crip, justice, and radical worlds. My interlocutors and their work lives and flourishes within the liminal space between these worlds. As such, so does this thesis. And by doing so, it begins to build bridges between these two bodies of literature and action.

Fifth and finally, the applied fields of global mental health and international development, and the global disability movement are all focused on human rights, often claiming that disability justice is ‘pie in the sky’ kind of thinking in the global South. I show that it is indeed ‘pie in the sky’ and that this does not make it irrelevant. It is exactly this kind of thinking in combination with actually actioning disability justice which makes the concept relevant in the global South. This is both a challenge and an addition to the actors in these fields.

Most importantly, I refuse singular ideas, frameworks, activism and show how plurality works in practice. And in doing so, make empirical interventions to multiple bodies of literature.

#### *Methodological interventions*

My research is shaped by the methodological choices I made in line with my theoretical and epistemological principles and sometimes driven by necessity. Three decisions, in particular,



make key methodological interventions: first, starting my fieldwork with those who are at the margins of the most visible part of psychosocial disability movement; second, disability as not only the substantive content of my thesis but also as a method; and third, understanding knowledge creation as a somewhat messy process, a mess which does not necessarily need to be neaten but rather is generative.

Starting with interlocutors at the periphery/margins problematised assumptions in other approaches to psychosocial disability like the ones outlined in the sub-section above. Empirically, again and again, the focus on marginalised groups' activism enabled a more nuanced and sometimes new readings of disability. For instance, an engagement with queer mad folks enabled a queer reading of the MHCA. It added complexity to the undermining effect of the legal provision of guardianship on mad folks by highlighting that guardianship could also include "radical understandings of family" (*Falak*) outside of blood or marital families. A focus on folks who are multiply marginalised enabled an analysis of how NGOisation and fascism work together within activism. While issues of professionalisation, neoliberal logics, and individualisation are well-documented within social movement literature, as are the chilling and violent effects of fascism, my interlocutors who stand at the intersection of these forces enabled an analysis of how these forces work together to create a reward and punishment system which excludes politicised action. Furthermore, a key part of untangling how elitism and power function to shape the priorities of the psychosocial disability movement, narrowing its remit, was only possible because of the insights of those who stand outside of the privileges afforded to the elites.

Critical to my thesis was not seeing marginality and privilege as static positions, but rather as relational and layered. Disabled people, including those with caste, class, gender, sexuality, religion privileges are marginalised within society. Axes of psychosocial disability or location within the global South can add to this marginalisation in some contexts. The aim was not to create a hierarchy of oppression or marginality or to find the *most* marginalised. Rather my methodology and analysis showed me that the tools afforded to us by our privileges fluctuate, and we can either use them to further entrench the systems which afford us this privilege or in solidarity with those challenging them.

Second, I am a researcher with a disability, but beyond that I am a mad disabled researcher. By that I mean that I am invested in anti-ableist action and consider myself as part of the broader project undertaken by disabled and disability activists. It also meant doing this research in ways that would accommodate my needs/being, being explicit about those ways, and in doing so

undermining the ableist expectations of academia. In Chapter III, I provide many examples of how I crippled methodology—expressing my vulnerabilities and access needs; reframing digital settings as just an extension of our lives and worlds; finding and creating access intimacies; talking to interlocutors with unwashed messy hair from bed and leaving behind the performance of a hyper-competent researcher; embracing or at least tolerating abrupt ends, lost thoughts, last-minute cancellations, and tangents.

All these examples are important interventions for other disabled researchers and researchers working with disabled communities. However, they are also critical for all academics and researchers. Through embodying disability as method, I draw out a critique of the hyper-productivity and hyper-competence demanded by the increasingly neoliberalised university. In our writing, our research, our presentations, we are expected to confidently present our work as conclusive and comprehensive and as a result of tireless and continual work. Disability as method says fuck that. Like my interlocutors, I too found myself looking for and leveraging small pathways and moments within the university. Struggling with anxiety and public speaking, I began to refuse to try and cover it up. When I was tired or in pain, I sat down and simply read a presentation instead of masking or medicating my pain and fatigue. I learned to say, “I don’t know” and “I can’t do this” when I could afford to. As I write this, I am keenly aware of how small these acts of defiance are. But as my interlocutors have taught me, small actions in service of big bold dreams are the stuff from which transformation is made.

Finally, my methodology is not necessarily about coming to a singular answer or conclusion. It is a methodology that rejects the certainty and comprehensiveness demanded of us from academia. It mimics what I found and the ways in which my interlocutors live and work, i.e., it “ask(s) difficult questions but accept(s) provisional answers” (Garland-Thomson, 2011, p. 40). In my writing, I have tried to create room not to dismiss or accept the more radical position but rather show that the ways people create practices and knowledges between/through disrupting binaries that are conceptually generative.

#### *Broader literatures/ concepts and for movements*

My empirical work illuminates what intersectional and crip disability activisms, in the context of capitalism and fascist political forms, look like, can be, and can do. The intervention my thesis offers about the transformative potential of crip organising has implications not just for us as disabled folks, but also for those who might not identify with/as disabled. Crip ways of being and thinking have a lot to offer to activism and scholarship across multiple issues.

Social movement frameworks expect and focus on a linear, cumulative, goal directed, success-driven, spectacular mass-mobilisation as *the* definitive form of social movements and activism<sup>69</sup>. My thesis provides an example of a ‘movement’ and ‘activism’ which subverts this expectation and shows an alternative vision of what radical action could look like. My interlocutors work within the hostile world as it is with the material realities of capitalist and fascist societies, and at the same time refuse to accept that this is all there is and can be. Like many others located in sites of struggle like climate change, settler colonialism, policing, and capitalism, they live and work in the chasm between what we dream of and what we live in and all the tensions that this presents. However, by refusing to choose one side or another, my interlocutors understand this tension as productive and generative. They use it to enact their dreams within their zones of action, i.e., they put their dreams into practice in the everyday. For them, as it is for Lorde (1982), “Revolution is not a one-time event. It is becoming always vigilant for the smallest opportunity to make a genuine change” (para. 24). They are not overly focussed on solving the contradictions that they are presented with because perhaps they can never be solved. But they do not sweep these contradictions under the proverbial rug, rather they are explicit about them, the kinds of pitfalls and challenges they present, and the strategies they require.

Questions of abolition vs reform and the engagement (or disengagement) strategies they require have relevance beyond psychiatry and disability. In their ‘doing’, my interlocutors eschew ideological purity and rigidity but rather practice ongoing thoughtfulness about and weighing of the potential impacts of their actions within their context. My thesis argues against purist ways of doing disability and activism more broadly. However, that does not mean opportunism or haphazard action. Like many abolitionist scholars and activists, I argue that strategic engagements and leveraging available opportunities, for my interlocutors, co-exist with some shared values that they are bound by (Kaba, 2021; Shehk, 2021). There are two major ways this is made explicit: one, their articulation of their utopian worlds which drive their efforts; and two, their knowledge of and concern with co-option and collusion. This is what separates their action from plain old reform or despair.

A shared radical dream and vigilance against co-option can be protective against the co-option and the subsequent hollowing out of our actions. These facets of activism come about only through centring the concerns, lives, knowledges, and practices of those who are intersectionally

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<sup>69</sup> The popular book *If We Burn: The Mass Protest Decade and the Missing Revolution* while very illuminative in its study of many different movements fundamentally understands revolution as a one-time event and hence describes it as missing (Bevin, 2023).

marginalised. Through this process we can begin to name interlocking systems (in the plural) as harmful and imagine worlds which are not just liberatory for some of us, but for all of us.

Through this process we can begin to untangle the systems and structures which seek to co-opt our activisms and the ways they function in society and within our activist settings.

None of the above insights are particularly new to those who live in abolitionist, decolonial, or other radical intersectional and inclusive activisms. As much as my thesis is an invitation to the disability movement to learn from my interlocutors, it also provides examples of how crip lessons can be incorporated within other activisms and movements. As many of us know, the kinds of work I describe above are continual and exhausting and lend themselves to burnout. A crip perspective—a vision of activism which is distributed and works through multiple unknown actors—is not just a tactic or strategy. It is a survival mechanism, for us as individuals and for our movements. Disabled leadership and involvement within climate justice, anti-colonial, anti-capitalist, anti-fascist movements is sometimes overlooked while at the same time the numbers of those disabled by these systems increases. For our movements to survive, we must ‘crip’ them. This means thinking about accessibility not just as a demand but as a practice within our movements. It means reinforcing the idea that rest is critical, and we need not feel shame for needing it. It means that we cannot demand one person or a few persons to shoulder the responsibilities, rather we need to create a network of collectives where we can step away for a while without causing the whole to fall apart. It means caring for each other, not as individualised actions, but as a crip principle of interdependence and vulnerability.

#### **8.4 What was left unsaid? Absences and silences**

Although my thesis never aimed for comprehensiveness, there are some absences and silences I want to comment on. First, there are things I left out in my discussion on activism in the face of fascism and the kinds of tactics that can be utilised to circumvent its tentacles. Publication of such actions has the potential to cause harm. Furthermore, academia and research are not the only ways knowledge travels and neither is it entitled to all knowledges. I learned a lot from some of the things I chose to leave out and I ensure that I pass it on in ways that are helpful.

Second, almost the entirety of my thesis is focussed on madness which is experienced as distressing. There are experiences of alternate realities/unusual experiences which people do not find distressing. Clare (2017) argues that a focus on structural analysis of root causes of madness erases those experiences. While some interlocutors referred in passing to the joy of madness, none of them described their madness as primarily joyous or non-distressing. I wonder if it is because so many participants face marginalisation in many ways and the distress from those

experiences influence how they think about madness in general. Or perhaps psychosocial disability as a concept attracts those who experience madness as distressing. In either case, it is an absence that is noteworthy.

Third, there was remarkably little said about global mental health or international development. I had expected these to feature heavily but almost none of my participants talked about them at length. I could read this in several ways. Maybe psychosocial disability is something that does not circulate in those settings and they are more focussed on mental health. Maybe, although unlikely, they are not very influential in general. Or maybe they have become too ubiquitous as influences that they no longer need to be named separately.

There are gaps, silences, and tangents unexplored in every research and as importantly there are entire pathways which are left untrodden. Psychosocial disability is only one of many ways of framing and mobilising mental (ill)health and disability politically. As I pointed out in Chapter IV, psychosocial disability is an English language term and is hence currently accessible only to a small sub-section of people. My interlocutors' introduction to psychosocial disability is mediated through their position as part of that sub-section. I chose to use psychosocial disability as my starting point and as such did not go down many other pathways. A different starting point would have unearthed different critiques of mainstream disability literature and yielded different ideas and frameworks of political madness. For instance, if I had started my examination with the aim of understanding how disability and mental ill-health are understood and done within Adivasi struggles, different English language terms such as "mental justice" as well as others in several languages would have emerged. While my interlocutors include aspects of other lineages of understanding madness into the ways they understand and 'do' psychosocial disability, they are not rooted in those traditions. As an example, like for my interlocutors with psychosocial disability, the term mental justice for indigenous activist Deepa Pawar highlights that mental health issues are linked to "the injustice, discrimination or violence that they have faced directly or indirectly because of being a part of said minority community" (Anubhuti Trust, n.d., para 1). However, understandings (including non-textual) which emerge from the deep connections between madness, development, coloniality, and land remain outside the work of my interlocutors and hence outside the scope of my thesis. Like Madhok's (2021) work on unsettling the origin story of human rights by very deliberately using the concept of *haq* as her starting point, I wonder what meanings of disability and mad justice we might find within different entry points and in other subaltern struggles.

## **8.5 Concluding the conclusion**

decide to become illegible, no universal, no binding struggle that means one thing and one thing only at any given time—only pockets of continuous action, non-action, faceless contribution, thankless labour, all in the spirit of quite simply, we will not tolerate suffering. repetition. here are strategies for resistance, they're not total, they're not right, they are there. pick them up and put them down depending on the horror of the day. don't waste time being surprised by the horror. no more performance for surveillance capital, and friends—whisper only one promise, to remain steadfast in the belief that this cannot be all there is. (Olufemi, 2021, p. 11, emphasis in original)

The work of my interlocutors reminds me of this moving passage by Lola Olufemi (2021). By refusing a singular framework to understand distress, they are refusing to be slotted into a category. They reject the idea that our struggles are the same and look the same. They value action and non-action equally, knowing that friendships and community are as important a site of activism as mass mobilisation. They are clear that theirs is a struggle that is ever evolving. They do not present their strategies for resistance as the 'right ones', rather, they present them as what they think is suitable for the moment. They live often in very different locations and worlds, and they work on issues and in ways that sometimes have little resemblance to each other. But they are bound by their refusal to "tolerate suffering" and their dreams of justice are underpinned always by "the belief that this cannot be all there is".

A while ago, I was scrolling through some social media site or another and I came across a post that said—everything is about reaching the ending, except for the ending which is about wanting to go back to the start. I can no longer remember where or in what context this was written, but it came to me when I started writing this conclusion to the conclusion. Where did I start? In my information sheet, I found this sentence: "Fundamental to this research project and to my broader interests, are questions of injustice, of power imbalances, of oppression and exclusion, but also equally of resistance and solidarities, of inclusive movement-building, and of creating communities and practices of care". And I think this is also where I have ended. So, in conclusion, my interlocutors work on and with psychosocial disability by mobilising it to address larger questions of injustice, of power imbalances, of oppression and exclusion, but also equally of resistance and solidarities, of inclusive movement-building, and of creating communities and practices of care.

## Afterword

जो खत्म हो किसी जगह

यह ऐसा सिलसिला नहीं<sup>70</sup>

*When I first started this PhD, I was lucky enough to receive a wealth of advice. My supervisor once told me, “There is the work and there is the PhD and the two are not the same”. A friend told me, “This is not the thing you will do, it’s just a thing”.*

*Endings are hard, they are coloured by all the things I would have done differently, regrets of the things I did not do, the scary uncertainty of whatever lies beyond it, and they bring grief and fear. For a while, ensconced within the words of my interlocutors, I too felt like I was part of their communities. But now I must leave their words behind, try to hold on to the lessons of their stories, and forge my own stories. And I really really hope that I have, somewhere inside me, the little embers of light and fire stoked by friendships and love, which will allow me to keep trying even when it all seems a bit futile. Please let this be only a thing I did, amongst so much more.*

*And hopefully, I will continue to unlearn resilience, I will continue to learn to rest, to tear down and to build up, to check in with friends, to organise protests and potlucks, to dream big and do the small things which will get us there.*

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<sup>70</sup> A couplet from the song Abhi Na Jao Chod Kar.

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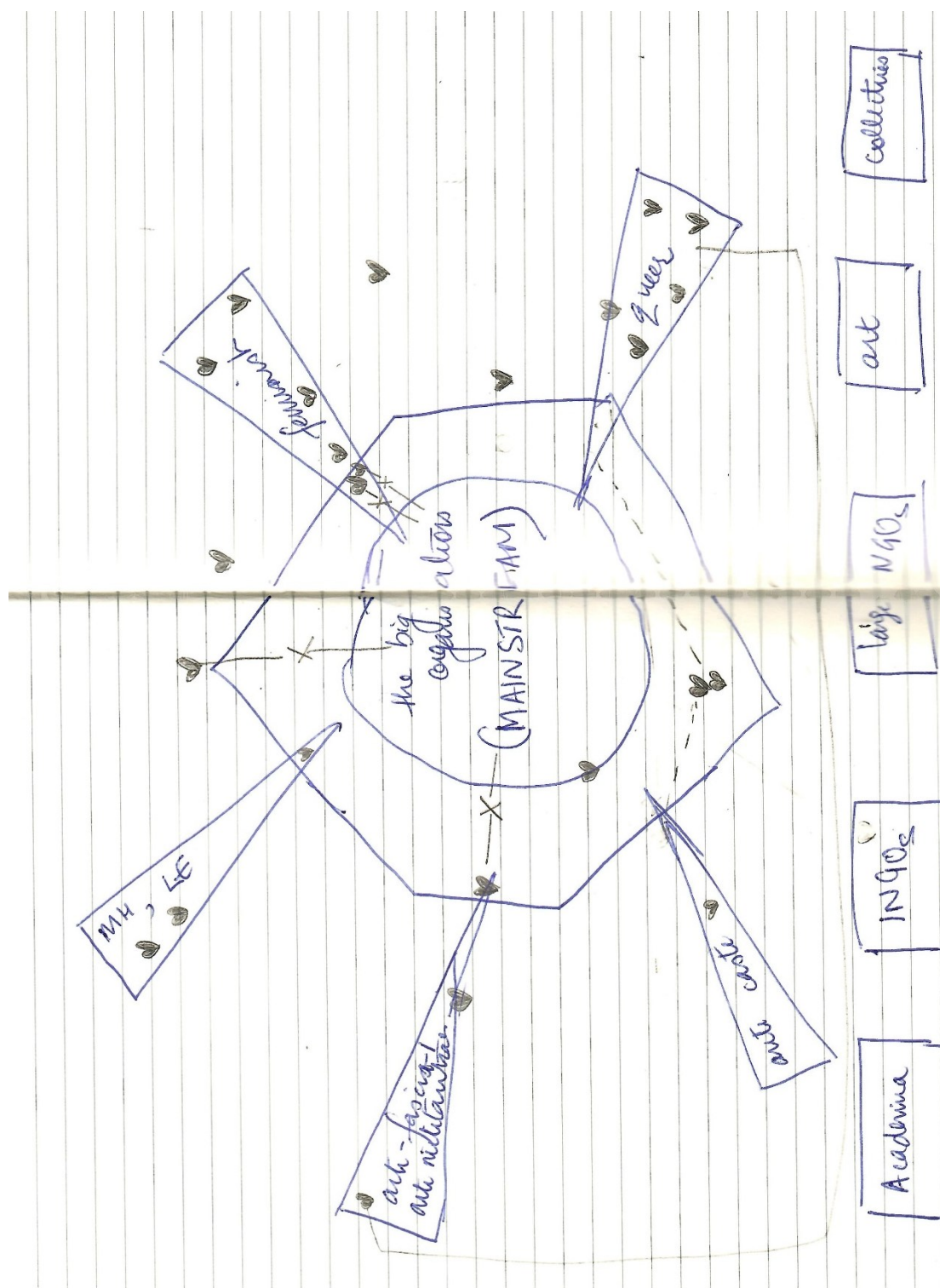
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## Appendices

### Appendix A: Mapping attempt



## **Appendix B: Information sheet**

### **Participant Information Sheet**

**Title of Study: Examining ‘psychosocial disability’ in India: construction, concerns, collaborations, and contestations**

#### **What is this research about?**

This research is about the emerging concepts, frameworks, and identity locations within mental health and disability activism in India by people with lived experience of mental (ill)health and psychosocial disability. It is particularly interested in the intersection of disability and mental health and the emergence of concepts such as ‘psychosocial disability’. It will explore how mental health and disability concepts emerge through activism; how they are mobilized by activists with lived experience of mental (ill)health and psychosocial disabilities; and how mental health and psychosocial disability activism is influenced by and in turn influences broader cross-disability activism.

This research project centers the global South, especially India, and the knowledges and experiences of activists with psychosocial disabilities. It rejects a purely biomedical understanding of mental health, rather it aligns itself with the approaches advanced by disability activists and scholars. The research views experiences of disability as multi-faceted and will privilege the work and voices of those who experience multiple marginalisations in India.

#### **Who is doing this research?**

The research project is being conducted by Akriti Mehta (under the supervision of Dr Flora Cornish) as part her PhD programme in the Department of Methodology, London School of Economics and Political Science.

I (Akriti Mehta) have experienced mental (ill)health and mental health services in India for over two decades. This experience of being categorised, ‘treated’, how my small acts of defiance were received by professional, professors, and society, and most importantly, the work of others taught me to critically re-examine my mental health experiences. I understand them as not merely medical matters but rather through a socio-political lens, mediated through my caste, class, sexuality, and gender locations.

I moved to London in 2016 to undertake a Masters’ course and stayed on as a researcher on a project which explored knowledge generation by mental health service users, survivors of psychiatry, and persons with psychosocial disabilities across the globe. This work experience, in

addition to my collaborations with global psychosocial disability activists, inspired me to undertake this project which centers disability perspectives emerging from India. Fundamental to this research project and to my broader interests, are questions of injustice, of power imbalances, of oppression and exclusion, but also equally of resistance and solidarities, of inclusive movement-building, and of creating communities and practices of care.

Dr Flora Cornish is my PhD supervisor. She is an Associate Professor at the London School of Economics who specialises in qualitative research and community development. Her focus on grassroots mobilization, community collaboration, and inclusive knowledge generation inspired me to reach out to her for this project.

### **Why am I being invited to take part?**

You are being invited to take part in this research group because (1) you have experience of activism led by mental health service users/persons with psychosocial disabilities, or (2) you have experience of and involvement in cross-disability activism and knowledge production.

### **What am I being asked to do?**

You are invited to take part in an online interview with Akriti Mehta. The interview will last approximately 1 hour and will focus on your experience and understanding of mental health, psychosocial disability, and/or cross-disability activism in India. In advance of the interview, you will be sent a list of topics likely to be covered in the interview. I will ask your permission to audio-record the interview.

You do not have to answer any question you don't feel comfortable answering, and you may withdraw your consent at any time. I will only use the data with your consent.

After the interview has been completed, the recording will be transcribed. You will receive a copy of the transcript and have the option to check it over. If you choose to take it up, this will give you the opportunity to confirm that you are satisfied that the interview accurately represents your views.

All transcripts will be compiled together, and Akriti (under the supervision of Dr Flora Cornish) will analyse them to come up with general findings. The findings will be reported anonymously unless you specifically prefer to be identified. You can indicate your choice—to be anonymous or fully identified—either before the interview or after you have reviewed your transcript.

The data will be stored securely for 10 years to allow the researcher to do them justice in analysing them and learning lessons. Afterwards, they will be securely destroyed.

In recognition of your time and expertise, you will be offered a payment of £30 (approximately INR 3,000) if you choose to participate in the project.

### **What will be the outcome of the project?**

The information you provide will help to map mental health and psychosocial disability activism as part of cross-disability activism in India. It will contribute to our understanding of mental health and psychosocial disability activism and advocacy and its relationship to cross-disability activism and knowledge. This may lead to increased visibility of mental health and psychosocial disability activism in India.

The results of the project will be published as a PhD thesis. I will also produce blog and journal articles which will be available to you. It might be suitable to publish the findings as part of a book.

### **Who can I contact about the research?**

We welcome your feedback on this research and your experience of taking part in it.

Akriti Mehta is the lead researcher with responsibility for this project. She can be contacted by WhatsApp or phone call on +44 7543 5193 66 and by email on [a.mehta29@lse.ac.uk](mailto:a.mehta29@lse.ac.uk)

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Thank you reading this information sheet and for considering participation in this research.

## **Appendix C: Consent form**

### **Consent Form**

**Title of Study: Examining ‘psychosocial disability’ in India: construction, concerns, collaborations, and contestations**

Thank you for considering taking part in this research. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to participate. You will be given a copy of this consent form to keep and refer to at any time.

Please type ‘yes’ or ‘no’ in the space provided after each sentence.

1. **I confirm that I understand that by typing ‘yes’ in each line I am voluntarily consenting to this element of the study. I understand that it will be assumed that leaving a line blank or typing ‘no’ in it mean that I DO NOT consent to that part of the study.** \_\_\_\_\_
2. I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information and have been given the opportunity to ask questions. \_\_\_\_\_
3. I understand that I will be able to withdraw my data from the study at any time or decline to answer any question if I so choose. \_\_\_\_\_
4. I would like to receive a copy of the transcript by email to review for accuracy, omissions, and any identifying information. \_\_\_\_\_
5. Anonymity is optional for this research. Please select from the following 3 options:
  - a. I agree to be fully identified. \_\_\_\_\_
  - b. I will inform the researcher about my decision regarding my anonymity after I have seen the transcript. \_\_\_\_\_
  - c. I wish to remain anonymous. \_\_\_\_\_
6. I consent to my interview being audio recorded, transcribed anonymously, and stored securely for analysis. \_\_\_\_\_

7. I understand the researcher will use material from the interview to write up a report and that quotes from my interview may be published and will be anonymised as requested on this form. \_\_\_\_\_

8. I would like to receive a copy of the publication(s). \_\_\_\_\_

_____	_____	_____
Name of Participant	Date	Signature

_____	_____	_____
Name of Researcher	Date	Signature

## **Appendix D: Interview topics**

### **Topics for interview – psychosocial disability activists**

- **Understanding ‘person with psychosocial disability’ as an identity and a framework**
- **Historical and contemporary shape of psychosocial disability activism**
  - Main activities – past and present
  - Influences
  - Engagement with human rights, development activities, community inclusion, research.
- **Intersections and alliances**
  - The relationship between psychosocial disability and other marginalised positions (such as gender, caste, etc)
  - Alliances with other movements (women’s rights, Dalit rights, movements against occupation, queer movements, regional movements, global alliances)
- **Collaborations with broader cross-disability movements and scholarship**
- **Future directions of the psychosocial disability movement**

### **Topics for interview – cross-disability activists**

- **Historical and contemporary shape of cross-disability movements**
  - ‘Cross-disability’ as a term
  - Activities and strategies of cross-disability movements historically and current.
  - Relationship between disability and other marginalised positions (such as gender, caste, etc)
- **Influence of psychosocial disability activism within cross-disability movements and/or scholarship**
  - The relationship between psychosocial disability/mental health activism and broader disability activism
  - Experience of working with psychosocial disability activists.
  - Research, scholarship, and theory.
- **Future directions for a cross-disability movement incorporating psychosocial disability**



## **Appendix E: Topic guides**

### **Topic guide – psychosocial disability activists**

- **‘Person with psychosocial disability’ as an identity and a framework**
  - How did you come to be involved in psychosocial disability/mental health activism?
  - Do you use the term psychosocial disability in your activism? Why or why not?
  - What is your understanding of ‘psychosocial disability’?
  - In what ways has this understanding changed over the years?
- **Historical and contemporary shape of psychosocial disability activism**
  - What is the main focus of your activism?
  - How has this changed over the years?
  - Would you say that there is a broader ‘psychosocial disability’ movement in India?
    - When did it start?
    - What are the main influences?
  - How do you engage with human rights?
  - How do you engage with development activities?
  - How do you understand community inclusion?
  - How do you understand the role of the government in your activism?
  - How do you understand the role of theory and research in your activism?
- **Exclusions, intersections, and alliances**
  - How do you understand the relationship between psychosocial disability and other marginalised positions (such as gender, caste, etc)?
  - How do you approach issues of privilege and power in your activism?
  - Do you have alliances with other movements? (women’s rights, Dalit rights, movements against occupation, queer movements, regional movements)
    - How did these alliances start?
    - What are the challenges of building such alliances?
  - What kinds of global alliances do you have?
- **Collaborations with cross-disability movements and scholarship**
  - How do you understand cross-disability movements in India?
  - Do you consider psychosocial disability activism as a type of disability activism?
  - What are the points of commonalities between them?

- What kinds of projects have you worked on with/within disability activism?
- How do you engage with disability theory and research?
- Can you tell me a bit about your experience of working with disability activists?
- **Future directions of the psychosocial disability movement**
  - What do you envision the future of psychosocial disability activism in India is?
  - Are you optimistic about the future of psychosocial disability activism in India?

#### Topic guide – cross-disability activists

- **Historical and contemporary shape of cross-disability movements**
  - How did you come to be involved in cross-disability activism/scholarship?
  - Do you use the term ‘cross-disability’ in your work? How do you understand it?
  - What is the main focus of your work?
  - Has this changed over the years?
  - Would you say there is a broader ‘cross-disability’ movement in India?
    - When did it start?
    - What are the main influences?
    - How do you understand the relationship between disability and other marginalised positions (such as gender, caste, etc)
    - How do you approach issues of power and privilege in disability movements?
- **Influence of psychosocial disability activism within cross-disability movements and/or scholarship**
  - What is the relationship between psychosocial disability/mental health activism and your work?
    - When and how did this start?
  - What is the relationship between psychosocial disability/mental health activism and broader disability activism?
    - When and how did this start?
  - What is your understanding of ‘psychosocial disability’?
  - What kinds of projects have you worked on with psychosocial disability activists?
- **Points of tensions between cross-disability and psychosocial disability activism**
  - What is your experience of working with psychosocial disability activism?
  - Did you face any challenges?

- Can you tell me a bit about the ways in which psychosocial disability changes/influences disability movements and theory?
- **Future directions for a cross-disability movement incorporating psychosocial disability**
  - How do you think we can incorporate psychosocial disability within cross-disability movements in the future?